

# “The 1040 Window”

Aaron Boydston’s Hospital Blog

Introduction .....	1
Chapter 1 • The Initial Trauma • May 16, 2006 – July 3, 2006 .....	2
The War with AML Begins .....	2
Into the ICU .....	4
Fevers Became Ferocious.....	6
Complete Paralysis (Medically Induced Coma) Begins .....	6
Two Nurses Needed.....	8
Getting Better and Praise God Party # 1 .....	10
Fevers Finally Fizzle .....	14
First Time Awake.....	17
Father’s Day: Gallbladder Removed and Aaron Speaks .....	26
Out of the ICU.....	28
Remission.....	33
Out of the Hospital.....	37
Chapter 2 • “Regular” Chemotherapy • July 4, 2006 – January 27, 2007 .....	39
Gaining Strength, Preparing for the Rest of Treatment.....	39
Second Round of Chemotherapy.....	42
Third Round of Chemo .....	48
Fourth Round of Chemo .....	54
Rigors .....	56
The Last Discharge.....	58
Chapter 3 • Relapse • January 28, 2007 – April 10, 2007 .....	61
The War Starts Over.....	61
Eye Pain .....	65
Heart Scare .....	66
Super Short Discharge .....	71
Excruciating Pain.....	72
Discharged, THEN Pain Relief .....	72
Real Remission.....	76
Lots a’ Radiation.....	77
Chapter 4 • The Final Battle • April 11, 2007 – June 20, 2007 .....	81
Transplant.....	81
Engraftment Begins .....	85
Engraftment is Officially Done .....	86
Mysterious Fevers .....	87
Blood Draws Become VERY Painful.....	88
Out of the Hospital .....	91
Back in the Hospital.....	93
The Real Last Discharge .....	94
Tired of Being Nauseous .....	96
Home for Good! .....	100

## Introduction

This compilation/organization of my hospital blog is dedicated to my dad, Ken Boydston. Because of his diligent journaling I have a written record of the events that I have little to no recollection of (most of the days I was in ICU). After Natalie, my Mom, and I took over the task of blogging, it was his diligent posting at the beginning that set the pace for us to continue giving regular updates.

This document is simply all the Hospital Log posts compiled into chronological order and organized into chapters and sections with headings (much, much easier to read than archived posts).

With very few exceptions, all the posts are exactly as they were when originally posted, *with spelling mistakes and all*. My reason for doing this is I feel it preserves a certain “character” of the posts. Consider the mistakes you find a representation of us “being in the midst of an intense struggle.” Any edits or notes I did make are in brackets [like this!].

Please note that the hyperlinks no longer work.

If you do not have time to read this entire story, since it is very long, I recommend you read Chapter 1. The “ICU days” (The Initial Trauma) were the most “exciting” and “drama filled;” very intense reading.

“To Live is Christ,”

Aaron C. Boydston

## Chapter 1 • The Initial Trauma • May 16, 2006 – July 3, 2006

### *The War with AML Begins*

[Hello world!](#)

Aaron asked me to set this blog up so he and his family can keep everyone up to date as he is being treated for leukemia at UCLA Medical Center. Please be prayerful in reading and responding to what will be written here.

- nathan stryker

[10 Comments »](#)

**May 16, 2006**

[The Journey So Far...Day 1 Tuesday 16 May, 2006](#)

It seems like Aaron has had a flu hanging on for 3 or 4 weeks. Nothing that couldn't be ignored. Tired, run-down, aching joints. Missed a couple days of work. But today, he is getting some bad headaches, dizziness, a little shortness of breath, and fever. It's enough worse enough that maybe a trip to the doctor this morning seems in order. Doctor looks him over, takes a blood sample, thinks maybe it's an infection. Aaron goes home with antibiotics. Doctor will call when blood sample tests come in. By late evening, Aaron is definitely not feeling well, and notices small red spots on his skin [and has a very difficult time breathing]. Natalie Googles the symptoms, and comes up with a couple matches: XXX and Leukemia. Of course, this can't possibly be, but she convinces Aaron to go to the ER at Ojai Community hospital. She calls Grandma Boydston a little before midnight and Anne makes the 5 minute drive to Summer and Signal. to watch Christopher and Michaela while she takes him. Anne calls Grandpa B as he is leaving work in Santa Barbara, just starting the one-hour commute to Ojai, to let him know she won't be home.

**May 17, 2006**

[The Journey So Far: Day 2 Wednesday 17 May](#)

[It is after midnight,] Dr. Williamson is on duty at the ER. Williamson is a glass-mostly-empty kind of doctor who looks for worst. He looks at Aaron, sees something he doesn't like, and has Aaron's blood driven the 20 miles to the nearest 24/7 blood lab in Ventura.

The lab numbers don't make sense. How can a WBC (white blood cell) count of 200,000, (200,000 cells/microliter, [normal is between 4,500 and 10,000]) be possible? Drive another blood sample to Ventura to run the test again, get on the phone with UCLA. Dr. Lee at UCLA confirms: This is Acute Leukemia, hyperleukocidic and most likely myelogenous. This is a medical emergency. This will require immediate, dramatic, and heroic intervention.

How can it be that Aaron, breathing a little hard but sitting up and cracking jokes, is so near death? The battle begins. Dr. Lee, acting as remote observer, calls in fire. The volleys are liquid, flowing from little plastic bags hung on a post, down through transparent plastic tubes, through a hollow needle penetrating the enemy's usurped domain.

UCLA prepares a room. Preparing a room isn't just changing the bedsheets. Legions of technicians, nurses, specialists, doctors, administrators, equipment, supplies, and chemical weapons of mass destruction must be ready when and as needed to effectively wage war. The medical team assembles, and begins to map out strategy. An ambulance is called to make the 75 mile trip from Ojai

to Westwood.

It's just after noon when Aaron arrives at UCLA Medical Center, West Wing, Room 1040. Within minutes, he's a tangle of tubes, a warren of wires, as he is connected to the machines of war.

There are 2 immediate critical things to do:

Reconnoiter....Begin the lab tests to assess the enemy

Destroy.....Get rid of a few billion Leukocytes.

This cancer is spawning millions of white cells per second. White cells (leukocytes) are supposed to help the body by destroying invaders...fighting disease. But the enemy cells are teenage mutant turncoat cells...huge, sticky premature mutants destroying the body they are supposed to protect. Teenage gangs run amok. And their numbers are overwhelming. They multiply, clump together, stick to the cell walls, turn the blood white. Destroy everything by their overwhelming numbers.

The plan of attack on these mutants is simple: poison them to death, and poison the mutant bone marrow cells that are spawning them. Unfortunately, the poisons that kill the mutants will also kill billions of good cells. Killing the mutants will make Aaron deathly ill. Of course there is no choice, as the mutants are nearly victorious already.

But there's a problem. The mutants are so profuse, too many good cells will die before the mutants are destroyed, and there will be so many dead mutants that even in death, they may strike a fatal blow.

An ice cream cart bristling with knobs, wires, gages, displays and tubes is wheeled in. Two of its many tubes are connected to Aaron; one to suck his blood out and another to spit it back, sans about 1/3 of the mutants, which will be removed by a centrifuge hidden in the bowels of the ice cream cart. Unfortunately, the mutants are about the same density as platelets, so, not unexpectedly, he needs a platelet transfusion.

After this, Aaron looks a bit improved

The first preparatory poison begins to drip. Not the main attack, just some preliminary strikes to soften the enemy....down the tube, thorough the needle, and into the enemy's camp.

[3 Comments »](#)

**May 18, 2006**

[Day 3: Thursday, 18 May 2006](#)

WBC down to 128,000. Not low enough, so in comes the ice cream cart. Aaron is connected, and the blood scrub (leukaphoresis) begins again. A few problems, blood doesn't want to flow too well, but they manage.

Bloodscrub looks good, WBC count down to 75,000. Get the main line ready for injecting the heavy duty poison. The heavy duty poison can't be injected into a wimpy little vein in an arm or a leg, as the poison is too toxic. It needs to get mixed immediately with a big volume of blood, so a "PIC" line, is inserted into Aaron's upper left arm and guided with ultrasound all the way to the superior vena cave at the entrance to the heart's right atrium.

As a last check, just before starting the poison, Aaron is x-rayed to check on the exact placement of the PIC line nozzle where the poison meets the blood. The doctor isn't happy with the placement, so out comes the PIC line. Another line is needed. But by now, the WBC has rocketed back up to 120,000. It's too late now for the major poison; the window is missed. Another bloodscrub will be needed tomorrow.

May 16, 2006 – July 3, 2006

Aaron's breathing is harder, more labored. Bump up the Oxygen. X-rays indicate something in the lungs. Pneumonia? Leukostasis? Crank up the antibiotics, just in case.

Second day of induction: "induction": fancy word for dripping cytotoxins (cytotoxins:fancy word for the poisons, just slightly more poisonous to cancer cells than to healthy cells, i.e., the "Chemo" in "Chemotherapy)) into Aaron's blood.

The leukemia is confirmed to be as initially diagnosed: Acute Myelogenous Lukemia (AML).

## **May 19, 2006**

### [Day 4: Friday 19 May 2006](#)

Get the PIC line in, check it, its good.

Bring in the ice cream cart and do the 3rd blood scrub.

WBC under 100,000

Late afternoon, bag is hung, the IV controller opens a valve and the main attack begins. Powerful poison begins its silent, steady, deadly drip. For 3 days, the poison Idarubicin will mete destruction upon the mutants, while receiving ongoing support from the Cytarabine, already dripping since Wednesday night, and scheduled to continue its destruction for 7 days.

## **May 20, 2006**

### [Day 5: Saturday, 20 May 2006](#)

Aaron's getting more listless, agitated, focused on breathing, eyes closed most of the time, sometimes dozing and hallucinating. Coughing off and on. Coughing hurts.

Dr Lee does the bone marrow biopsy. Aaron lays on his stomach, doctor probes around just above left butt cheek, looking for a place to probe. Finds what he wants, swabs the area with betadyne and alcohol, injects lidocane just under the skin, pokes deeper with the lidocane needle, injects more, buries the needle injects more. Changes to a longer needle, goes deeper, changes to a really long needle and goes to the bone. Makes a small incision, then grabs a widgeit that looks like a blue T-handle ¼" hex key and plunges it to the bone. Pokes around on the bone to find a good entry spot, then with a mighty push, he shoves it deep into the pelvis. The T-handle key is actually a miniature coring drill, such as might be used to extract ice from deep below the polar icecap. 30 minutes later he gets what he's after.

Breathing is increasingly labored. We were warned that Aaron is heading for ICU. ICU doctors check every hour or so, monitoring his status and asking us (like we're the experts) what we think...is he more alert? Less? More confused (he's been hallucinating off and on....firefighters, lemons, and limes)? Less confused?

They bump up his oxygen, put on a different mask that gives more moisture, and it seems to help a little.

## ***Into the ICU***

## **May 21, 2006**

### [Day 6: Sunday, 21 May 2006](#)

Finally, at about 5:00 AM, he's not able to breathe well enough to keep his blood oxygenated. While the blood oxygen isn't critically low, he is behaving as if it is; he's seeing Vikings and other manner of people that aren't. Of course, with such a cocktail of drugs and poisons circulating through his brain,

an induced chemical imbalance could also account for the visions. But there's no denying the labor of his breathing, and the amount of effort Aaron is expending to stay alive. He seems to be focused (when not confused and hallucinogenic) on breathing...eyes closed, intense, suddenly asleep, awake again a minute later. He needs help.

Help comes by way of a tube down the throat directly into the lungs and hooked up to an air pump that forces oxygen directly into his lungs.

Getting the tube into the lungs is a problem.... it goes down wrong; the chemo enhanced nausea needs but a tickle and the air tube fills with whatever was in his stomach.

Second time's a charm; Aaron is sedated and the ventilator is working. But things aren't going well. To get a more real-time assessment of his situation, a Swan-Gans probe is inserted into the atrium of the heart. Another probe is inserted into an artery. These give immediate feedback to better manage the crisis.

The cancer, previously confirmed to be [sic]

[turn for the worse](#)

Aaron is in ICU. They had to intubate him to help him breathe, but he is still having trouble. Some stomach gunk got into his lungs during the intubation. Please pray!

[5 Comments »](#)

**May 22, 2006**

[Prayer](#)

Yesterday many relatives and friends arrived to pray for Aaron. It was a critical day and God was with us. Today he is stable and in the intensive care unit. For the next 48 hours he will be watched carefully. If all goes well, we can hope for a normal chemotherapy treatment and recovery.

[9 Comments »](#)

[Day 7: Monday, 22 May 2006](#)

Aaron is moved from the overflow basement ICU to a real ICU on the 4th floor. Now he's got a private room in the ICU, with its own HEPA air filter so that bacteria and other nasty stuff in the air is constantly filtered. 4th floor is more kicked back than 10th floor. People sleep all night in the [4th floor] waiting room. On the 10th floor, Anne and Natalie, getting a little sleep in the waiting room, get roused at 2am and told to go home. They stay anyway.

Bone marrow tests indicate AML is of subtype M5, Monocytic.

Aaron is having a rough time. He keeps up a persistent fever, occasionally high.

Every couple hours, blood tests confirm that there is no detectable infection.

Infection is the ally of the enemy: The enemy white cells' are subverted; they maintain no vigilance against foreign invaders; they are useless against infection. To make matters even worse, killing the enemy also kills what loyal cells are left, leaving Aaron defenseless and vulnerable to opportunistic bacterial, fungal, and viral marauders out and about, seeking that which they may destroy.

Aaron's fever spikes around midnight.

**May 23, 2006**

[Day 8: Tuesday, 23 May 2006](#)

Aaron is better today. The fever slowly retreats, and by morning he's a perfect 37C (Multiply by 9/5, then add 32 for last century's Fahrenheit units.)

Part of better is how he looks. Better, of course, is relative. Not relative to last Tuesday morning, 8 days ago, when he looked like Aaron. Looking that far back is as imprudent as looking that far forward. Relative to yesterday is our point of reference. A little less puffy, his swollen-shut eyes not quite so distended, his skin not quite so sallow, the sores not quite so raw. But if you look past the cyborgian tangle of tubes and wires protruding from every natural and inflicted orifice of his body, he looks better.

The other part of better is the numbers. There's lots of numbers, pages of parameters that are measured, compared, studied, and assessed. The doctors stare and scribble and question and comment. What does this number mean? But what does it REALLY mean in light of this other number? And what does this other number mean in light of such-and-such a drug, chemical, or procedure?

Bottom line, the numbers say Aaron is possibly just slightly better, so the doctors are pleased.

### [Remember](#)

Today, we are fasting and praying for Aaron's continued recovery and healing. If you're not called to fast, don't, but no matter what your beliefs, you can talk to God. If you believe in God, surely you believe God can heal. If you're agnostic, just tack on an "if You exist" to your prayer. If you are atheistic, just think nice thoughts about Aaron. The important thing is that everyone is petitioning to something bigger than themselves on behalf of our friend Aaron today.

[5 Comments »](#)

### [Aaron and Christopher](#)

[sic – picture is missing, but there is one in comments]

This picture was taken over a year ago but it's the only one I have on hand.

[5 Comments »](#)

## ***Fevers Became Ferocious***

**May 24, 2006**

[Day 9: Wednesday, 24 May 2006](#)

Today started with a fever that spiked at 39.5C during the wee hours. The search for the fever source turns up no hint of infection. The fever persists, albeit lower, all day and into the night.

Until yesterday, Aaron has been getting 100% oxygen. Oxygen, not surprisingly, oxidizes stuff, and 100% oxygen will eventually ruin tissue. Yesterday the Oxygen was reduced to 70%, but today it's back up to 90%, as 70% wasn't quite good enough to keep up with the body's needs. It's pretty clear there has been some lung damage. Most likely the damage is from a condition called Leukostasis, caused by the legions of mutant leukocytes that were present a few short days ago. As of now, there are virtually no white cells left alive....just legions of dead enemy cells that are stressing all the vital organs as Aaron's body struggles to eliminate them.

Tonight, the last bag of Cytarabine will hang, and the initial onslaught will complete.

[6 Comments »](#)

## ***Complete Paralysis (Medically Induced Coma) Begins***

**May 25, 2006**

[Day 10: Thursday, 25 May 2006](#)



This has been a rough day. Aaron has been very unstable. His vitals are all over the map.

He's got a high fever, every indication of a systemic infection. Moving him just a slight amount to perform a procedure causes his blood oxygen to plummet. There's no place to go up, as supply oxygen concentration is 100%. All symptoms point to a systemic infection, but culture after culture reveal nothing. Every point of entry (probes, catheters, IV's) is cultured for local infection; all are all negative.

The cold blanket brought in to help control the fever can't be put under him, as he is too unstable. The blanket is spread over him, but it doesn't work well. The refrigerator machine that pumps coolant through the blanket sits in the room. The room air conditioning can't keep pace with the additional kilowatt being dissipated by the refrigerator. The machine is stopped; Natalie and Anne take turns using low-tech, time-honored wet towels; this works. The fever comes down.

Camela (his CCU day nurse today) works non-stop, never quite getting ahead of the demands. It took two hours early this morning to regain stability. Stability is finally achieved, but comes at an unsustainable price: 100% oxygen, and 22 cm PEEP. (Positive End of Expiration Pressure). This means that all the tiny air sacs (alveoli) in Aaron's lungs are being constantly inflated like millions of tiny leaking balloons filled with pure oxygen. The breathing machine must keep the balloons puffed up to prevent collapse. Several quarts of extra fluid have accumulated in Aaron's body due to the intense hydration required for successful induction of the poisons, and the inability of Aaron's kidneys to eliminate the excess. The lung damage inflicted by the mutants (and possibly the poisons that killed them...there is some evidence that the mutants initially responded to the poison by further mutating, becoming more mature and more destructive.) is allowing these accumulated fluids to leak into the airways, so the leaky balloons have to be constantly inflated. The constant pressure and the pure oxygen, will soon destroy the lungs they are heroically working to save.

In spite of being heavily sedated, Aaron continues to initiate breathing on his own. This is of course a marvelous thing that living bodies are programmed to do without conscious effort: breathe. But the beat of the drum to which Aaron's lungs are heaving is too slow. He needs to be breathing like he's running a ¼ mile, not lounging on an air mattress (He actually is on an air mattress, which slowly inflates and deflates to provide a small amount of very slow movement to Aaron. Other than the machine-induced heaving of his chest and the slow, barely discernable movements of the air mattress, Aaron is completely still. The evidence that Aaron is alive are the numbers—numbers flashing on monitors, numbers of measurements from instrument probes outside and deep inside his body, numbers from computers calculating values from the measured numbers, numbers printed on test reports, numbers scribbled on paper, numbers that can lie to the ignorant, but render their arcane secrets those who, like Dr. Bajaj and Dr. Lee, seek the truth that lies beneath the numbers. This is medicine by the numbers: the numbers of life.)

The ventilator synchronizes its efforts with Aaron's lounging pace, but it's clear that at this point, the machine can do better if it could take over; Aaron's efforts have become interference. The decision is made, and in late afternoon yet another IV bag is hung along with the 14-or-so others that have been accumulating over the last week. Vecuronium Bromide begins to drip, totally paralyzing Aaron so he is unable to even attempt breathing. The machine is now in complete control. No part of the precious oxygen budget needs to power the lungs, and the machine's drummer sets the pace.

The improvement is immediate; a small window of margin opens. The moment-by-moment struggle for stability a little less intense.

Aaron's kidney's are doing a yeoman's job, but their efforts are not enough. Between the induced chemotherapy poison, the poisons created by dead mutants, and the great deal of other chemicals and fluid going in through the various intravenous tubes, his kidneys can't keep up.

So yet another machine is wheeled into the room, yet another couple needles are inserted, yet another couple tubes are connected.

Blood begins to flow through the Mechanical Urinator.

Aaron is on dialysis.

The Urinator works just a little faster than Aaron's own Lasix stimulated kidneys...with Aaron and the Urinator working together, he gets some breathing room.

A little after midnight, the Cytarabine bag is empty. The poison is finished.

[8 Comments »](#)

[Faith \(by Natalie\)](#)

I have been learning a lot in the last week about faith. It has been an overwhelming journey full of ups and downs but through it all I have tried to remember that God is controlling all things. Throughout the gospels, there are so many stories about how Jesus healed people out of His compassion because of their faith and for His glory. I am asking God that He would work the same way in Aaron's life. I am praying for God's compassion and mercy in this situation—we are His children and His love for us is so great. I am bringing Aaron to God believing that He is the Great Physician and that He can and will heal my husband. Above all, I am giving God glory for all that He has done for Aaron and will do. The important thing that I am learning is that our faith should not rest in the wisdom of men but in the power of God. Through all of the little successes and setbacks, I am praying for a strength that will keep me constantly trusting.

Thank you so much for all of you who have been praying. It is so wonderful to see so many people petitioning our Father on behalf of my husband. Please, continue to pray especially for his lungs to heal and his body to respond well to the chemo. The next few days are crucial in his recovery so keep that in mind while you are praying. I am overwhelmed by how much people are doing for us without me having to even ask: the RV, taking care of finances, bringing food, visiting!, etc. Thank you so much! An especially big thank you to my family for taking care of the kids. I'm looking forward to giving more Praise God reports in the future.

[10 Comments »](#)

## ***Two Nurses Needed***

**May 26, 2006**

[Day 11: Friday, 26 May, 2006](#)

Last night Aaron is double-teamed. Norma and Amelia work swiftly, each attending to different requirements. The Urinator provides Aaron some additional opportunities, which means additional observations, measurements, and adjustments. Aaron and his attendant machines together are a complex system requiring constant adjustments. As with modern, high performance aircraft, there are no stable trim settings. Just as these extreme fighter aircraft are aerodynamically unstable and stable flight is achieved through constant adjustment, Aaron is metabolically unstable and stable life is achieved only through constant adjustment.

Over the course of the day, the Aaron and the Urinator achieve a net loss of about 3 liters of fluid from his body. By the end of the day, the Urinator is outperforming Aaron's own kidneys by about 3 to 1.

The oxygen supply concentration is gradually lowered to 60-70% and PEEP is lowered little by little to around 10cm. These are much more sustainable values than yesterday's. With Aaron deeply sedated and paralyzed, the Ventilator is now firmly in control. Aaron's breath rate is increased to 35 breaths/minute. He may still be lounging on an air mattress, but his lungs are running the ¼ mile. At these settings, his blood oxygen saturation stays in the high nineties. This is a much-improved situation from yesterday.

But the improvements don't come without a struggle.

It's not enough that the lungs take in oxygen. They must also get rid of carbon dioxide. The faster breath rate isn't allowing enough time for the carbon dioxide to escape. The ventilator settings are tweaked to change the pressure waveform: shorten the inhale pressure pulse and lengthen the exhale relaxation time. This helps; the big yellow CO2 value the vitals CRT drops from 100 to 50.

Excess carbon dioxide in the atmosphere contributes to acid rain (as well as perhaps global warming); excess carbon dioxide in Aaron contributes to acid blood. The massive die-off of the mutants also contributes to acid buildup as they decay. Aaron's pH drops to 7.1 as the acid keeps building. Fortunately, there's ARM & HAMMER. One of the oldest and truest antacids can be injected straight into the blood. Whether it's controlling refrigerator odors, baking cookies, or restoring critical acid/alkaline balance, good old baking soda works. The pH is brought to a near normal 7.3.

Aaron doesn't look quite so bloated by the end of the day.

Pneumonia, never proved but strongly implicated and aggressively addressed with antibiotics, appears no worse.

There is no indication that the lung damage is worse.

His fever has abated.

His vitals are stable.

The constant hum of the machines, the compassionate competence of the staff, and the sublime grace of God give us hope for another day.

[4 Comments »](#)

**May 27, 2006**

[Day 12 Saturday, 27 May, 2006](#)

This has been a good day. Only a single crisis, and it was in the wee hours early, when for no obvious reason, Aaron's oxygen saturation briefly plummets.

It could be related to Aaron's odd reactions to the paralyzing drug. The Vecuronium doesn't quite work as predictably as it normally does. A small handheld machine the size of a 1994 cell phone injects a small current into Aaron's skin, and the muscle twitching in response to the current measures of effective the drug is working. Sometimes, with very little paralyzing drug, Aaron doesn't twitch at all, which means it's working very well; it is unwise for the paralyzer to work too well, as paralyzing his heart is not one of the treatment goals. Other times, with a fair amount of paralyzer, Aaron twitches a lot. So it's hard to predict just how much he needs. As a result, Aaron will intermittently still attempt to breath. When he does so, he overrides the ventilator and promptly gets into trouble, going quickly into oxygen deficit.

Kamela, who is on again today, grows a little exasperated as she attempts to tweak the untweakable. But it's a small detail compared to the crises of the last few days.

“Pneumothorax” is a fancy word for what happens if a blowout occurs. The high pressure puffs being blown into Aaron's lungs by the Ventilator risk blowing a hole in the delicate tissue. There is some evidence that that may have happened, so quickly more tests are done. A portable Xray machine is wheeled in again as it has been a number of times over the last few days. The Xray “film” (it's actually not film...it's a plate that yields its hidden image directly to the computer without needing chemical development). is slipped between slick surfaces under the air mattress. Aaron does not need to be moved; his delicate balance is not disturbed.

The image shows nothing. False alarm.

Aaron looks better, having lost about 8 pounds of water since the Urinator joined forces with his own kidney to mop up after the carnage wrought against the mutants.

The numbers of his life are better. His oxygen supply is sustainable.

This has been a good day.

[1 Comment »](#)

## ***Getting Better and Praise God Party # 1***

**May 28, 2006**

[Day 13 Sunday, 28 May, 2006](#)

Aaron continues to improve. Dr. Bajaj, who will take a well earned Memorial Day holiday tomorrow, confirms that Aaron's heart is working more effectively, his lungs are less leaky, his kidneys are working better, and he is regaining acid/alkaline balance on his own. These are all definite signs of improvement.

Aaron is given a brief holiday from the Paralyzer to see how he responds. He quickly demonstrates that he is still not ready to set the pace; his blood oxygen drops as he tries to over-breathe the Ventilator, so he is paralyzed again into submission.

Collateral damage from the slaughter of the mutants has seriously compromised the ability of Aaron's blood to staunch it's flow though leaky and damaged blood vessel walls. The mutants are dead, yet they mount a post-mortem attack on still another flank. Their attack is met with a plastic IV bag filled with a viscous, milky-white fluid.

Kim, his night nurse, explains as yet another bag of platelets she is transfusing disappears quickly into Aaron, that platelets, whose job in life is to clot, must be injected rapidly to keep them from clotting on the way into the vein.

Once in, the platelets keep his blood inside the vessels, preventing the vital flow from leaking out into lifeless and impotent puddles.

Ventilator settings of 60% oxygen, 35 breaths/minute, 30% duty cycle square pressure pulses and PEEP of 9 are sufficient to maintain 99% blood oxygen saturation.

Aaron's 5 quarts of blood continue to flow through the Urinator. Every hour, his blood completes the round trip twice, and every hour, another cup of pale yellow urine drips into the Urinator's polyethylene bladder; about half a cup more than is going into Aaron from the many life-giving bags constantly being hung on the IV rack.

A broad spectrum of antibiotics keeps infection at bay. The pneumonia is under control...there has been no fever.

Aaron is getting better.

[7 Comments »](#)

[Quickie Update \(Rose\)](#)

Aaron is doing better today, Sunday, May 28 than he was yesterday- and yesterday was a good day! Healing is taking place.

FYI: The reason this blog was entitled “The 1040 Window” is because Aaron was in room 1040 before he was moved to the ICU. We actually took a picture the 1040 window but it hasn’t made its way on to the blog. For those who don’t know the reference, the 10/40 Window also refers to the countries most in need of prayer which happened to be located approximately between 10 degrees and 40 degree North of the Equator stretching from Africa to China. Anyway, we thought the room number was appropriate. Thanks for all your prayers!

[8 Comments »](#)

**May 29, 2006**

[Day 14 Monday, 29 May, 2006](#)

Today is Memorial Day, a day of forgotten remembrance, more associated with pre-summer barbeques than with solemn remembrance.

Cherished friends of Anne & Ken, many of whom met at Harvey Mudd College in the early 70’s, have, for some 20 years, had a habit of amassing at Boulderhaven in Ojai around this time of year for “Star Gazing”, a weekend of gazing, grazing, and gabbing. Jon and [UCLA chemistry librarian] Marion Mercel who, with Pat Joyce, constitute this years quorum of gazers at the impromptu location outside Aaron’s private suite in the UCLA Medical Center 4th floor ICU.

Aaron’s continued improvement lends a festive atmosphere to the holiday. Natalie declares that we celebrate today “Praise God Party #1”, so a 20-strong contingent of family and friends descend upon California Pizza Kitchen in Westwood Village to rejoice. We are in a partying mood.

Clues to Aaron’s improvement are found in numerous places:

Ventilator settings are closer to normal: 40% oxygen supply saturation, PEEP of 8 or 9.

The Paralyzer was discontinued around noon; Aaron does well all day without it.

The under-damped ringing of the Ventilator Oxygen flow waveform has decreased to barely a ripple. This indicates increasing elastic compliance of the lungs.

Kim and Cheryl (night & day nurses) have more time to catch up with things like cleaning and grooming, so Aaron looks even better.

At morning rounds, the doctors spend less time, are not so somber, and make fewer changes.

The IV racks are less overloaded with bottles and bags of dripping medications, and the bags are changed less often.

Tested, measured and computed values—the numbers of his life—fluctuate less and trend toward normal.

There was considerable discussion among the doctors about discontinuing the Urinator. But it is agreed that it might be premature to do so....Aaron's boat is stable and heading in the right direction...let's not rock it too much all at once.

Michaela and Christopher return to Ojai with Grandma & Grandpa Metz after spending the long weekend at the Tiverton house with Mom and all the grandparents. They don't get to see dad.

At times, we almost forget about the cancer. But never quite....we wonder what is happening deep within the marrow of Aaron's bones. Is the enemy even now regrouping from last weeks devastating poison onslaught?

[5 Comments »](#)

**May 30, 2006**

[Day 15 Tuesday, 30 May, 2006](#)

Between Aaron and the Urinator, the Paralyzer has been flushed into history. When it began its work on Thursday, Aaron's sedatives (Propofol and Ativan...Aaron clearly prefers Propofol, but the doctors seem intent that he should have Ativan) were increased. The paralyzer Vecuronium does not suppress consciousness or pain....it is essentially a powerful muscle relaxant. Being conscious and paralyzed is frightening, so Aaron's sleep has been near comatose...in this deep-sleep state, Aaron could undergo surgery without pain. Today, with the Paralyzer gone, Ventilator settings closer to normal (40% Oxygen, PEEP 4, 30 breaths/minute, tidal volume 400), and Aaron beginning to take control of his own metabolism, the sedatives are intermittently reduced to see if he is ready to be weaned from the tube down his throat that delivers oxygen to his lungs. Aaron begins to surface for a few minutes at a time. Fran, his day nurse who is bound to have him up and walking sooner than later, allows him to surface to the point where, when she asks if he is in pain, he shakes his head. Another time, Natalie asks Aaron if he is uncomfortable: he nods.

He is intermittently aware of the tube down his throat. The more he is aware, the more he is wracked with an apparently overwhelming gag reflex. As the day fades toward shift change and into night, these intermittent spasms continue, and seem to worsen. His body arches in violent paroxysm; silent tears burst from his still-bloody, swollen, and mostly-closed eyes.

His systolic blood pressure shoots up to 160. The Ventilator senses that something is very wrong that it can't correct, and begins its wail of desperation. The creators of the Ventilator must have worked long and hard to give it this most disturbing and demanding voice. The Urinator complains less demandingly that blood flow is cut off, and it stops. It must be restarted immediately to prevent blood from clotting. On several occasions, it isn't restarted fast enough. The Urinator ups the ante of its compliant; the blood has clotted, and its filter must be changed. The spaghetti of tubing threaded through the Urinator like movie film through an old fashion projector is removed, The tubes are disconnected from spigots piercing Aaron, the filter is detached, a new set of tubes is threaded, another polymer kidney is attached, the tubes are reconnected to Aaron, and blood begins its tortuous round trip through the Urinator, as it begins to fill yet another bag with pale yellow urine.

We tell Aaron what a great job he is doing, that everything is going well, that he's getting better. It's hard to say that he is convinced.

The fever is back and rising

[7 Comments »](#)

**May 31, 2006**

[Day 16 Wednesday, 31 May, 2006](#)

The wracking and gagging continue through the night. Aaron sweats profusely at times; his fever rises. As he becomes more aware, he struggles to move limbs still laden with fluid (though drained considerably of some 2 gallons over the last few days) and bristling with tubes and wires. He is restrained for fear that he will rip asunder the conduits of life which connect him to his machines. The intense effort seems to exhaust him...the numbers of his life reflect the toll. Has he overspent his precious oxygen budget in fruitless struggle?

With morning and a new shift, Kamela observes his condition to the doctors. He is mercifully sedated more heavily, and rests somewhat easier for the rest of the day. The Fever persists, its source still a mystery. At 39.5 C, he is packed with ice. There is an enemy within seeking to destroy that which it may.

[2 Comments »](#)

**June 1, 2006**

[Praise and Prayers \(By Natalie\)](#)

This last weekend was amazing. I prayed that we would have a Memorial Day Weekend Miracle. God sure gave us one. Before the weekend started, Aaron's lungs were doing poorly but starting on Saturday, we began to hear word that he was turning around. There was such a dramatic improvement in his lungs. Praise God for answering that prayer of mine! We learned on Sunday night that the main doctor considered him to be in a recovery phase. On Monday, we even had Praise God Party #1! When you are praying for Aaron, please be sure to give God glory and thanks for the great things that he has done so far. By the way, Michaela (our daughter) got her miracle of healing on Memorial Day weekend 4 years ago—that is when her reflux was diagnosed and she began to eat.

Today, Aaron had a little bit of a setback. First, he got a really high fever. We are praying that his temperature will return to normal and that his body will recover from the chemo. Secondly, he was taken off of the sedation on Tuesday while he was still on the ventilator. For a while he was doing OK but he then started gagging on the ventilator for 12 hours straight. It was really amazing to see him open his eyes—he even started crying when he saw me. He also answered a couple of yes/no questions by shaking his head. Today, they had to bump up the sedation and try to get him regulated again. It was probably too soon to take him off of the sedation yesterday.

I have so many Bible verses that I am clinging to. God's Word is true! My verse for today is "But without faith it is impossible to please God, for he who comes to God must believe that He is and that He is a rewarder of those who seek Him." Hebrews 11:6. I am still praying in faith believing that God can, is and will continue to heal Aaron for His glory. When going through trials, God is interested in where our faith will be shown to be. I would encourage you to think about where your faith lies—is it the medicine, the doctors, God, something else? My faith is in God who created the universe—who created Aaron!—there is nothing that is too difficult for Him!

Thanks for the continued prayers and all that you all are doing. We thank you for standing with us. (If there are any Bible verses that God lays on your heart, send them my way!)

[3 Comments »](#)

[Day 17 Thursday, 1 June, 2006](#)

Our concerns seesaw in concert with Aaron's metabolism. Parameters so nicely behaved 3 days ago and trending better seem to have lost their compass and fluctuate wildly. Systolic blood pressure surges to 200 and plummets to 60.

Ongoing platelet transfusions aren't enough staunch the flow of Aaron's blood through leaky capillary walls. He is bleeding internally. But it's not like he is bleeding somewhere—he's bleeding everywhere. Transfusions of whole blood are begun. These, together with an open bar of medicinal cocktails, keep his seesaw within the bounds of life.

One of Aaron's life lines is the CVP (Central Venous Pressure. This dual use line provides a tube through which to ply Aaron with cocktails, as well a transducer from whose pressure measurements inside the atrium the effects of the cocktails may be surmised.) line which pierces through the right side of his neck into a vein and threads its way down into the right atrium of the heart. Kamala notices that the skin is a little red around the entry point. She also observes that, over the past few days, Aaron tends turn his head to the right, and drool tends to run down into the vicinity where the line pierces the skin. Perhaps this line is a hideout of the infectious allies of the enemy. The line has been in for a while, so even though days of negative cultures performed in the vigilant search for infection have turned up nothing, the CVP line is removed and reinserted into the left side of his neck. As a further precaution the arterial probe line is removed from Aaron's left wrist and inserted into his right wrist.

To further regain control and stability, the Paralyzer Vecuronium is re-enlisted.

Aaron is returned to deep sleep and the stillness of paralysis.

By midnight, his numbers are stable and acceptable.

The fever is under control.

Aaron is not ready to breathe on his own quite yet.

[4 Comments »](#)

## ***Fevers Finally Fizzle***

**June 2, 2006**

[Day 18 Friday, 2 June, 2006](#)

Aaron begins the day paralyzed and mostly stable. The fever continues to abate; by evening it is gone.

More platelets and blood (yesterday's post was in error. The blood transfusion was not whole blood. It was "packed cells", a sort of high-fructose corn syrup for vamps and patients with low hemoglobin. Packed cells is blood minus white cells and other stuff, leaving only red cells) are transfused. The hemoglobin count does not increase as hoped, but its downward trend stops and it remains stable.

Early afternoon, Aaron's blood pressure plummets. Perhaps the Urinator, which goes at the behest of its settings rather than on demand from Aaron, is going too much...perhaps Aaron is too dry. Before taking more drastic measures, Kamala throttles back on the Urinator, opens the spigots of some IV fluids, and transfuses more blood and platelets. Slowly, the pressure rises to less alarming levels and eventually returns to normal.

For the last couple days, the Urinator's output has been tapering off as Aaron's kidneys take on a greater share of the load...Aaron is outgoing the Urinator by about 1/3.

Between the 2 of them, they are outputting just about the same amount as is being dripped, injected, transfused and dialyzed in.

It's a tricky balance with leaky blood vessels. The heart likes it wet; the lungs like it dry. Too dry, the heart can't pump; too wet, the lungs can't breathe.



At noon, the Paralyzer Vecuronium is stopped, and over the ensuing hours Aaron remains deeply sedated and stable without requiring its merciful but dangerous services.

[1 Comment »](#)

**June 3, 2006**

[Day 19 Saturday, 3 June, 2006](#)

Aaron continues stable without the Paralyzer through the night and into morning, deeply sedated, and compliant with the Ventilator. Sustainable settings of the Ventilator maintain good oxygen levels. During the day, the givers of his sleep are withheld just enough that he occasionally, without harm, bucks the Ventilator; he is not awake enough to be gagged by the life-giving endotracheal tube through which the Ventilator provides it's invisible vitality.

His blood pressure vacillates on the low side of normal, and despite the last 2 days of transfusions, his hemoglobin count remains low. There is the nagging suspicion that, in addition to systemic leakage, there may be localized bleeding. A picture of his insides could help assess the damage wrought by the enemy. A damage report is needed; the report requires an elevator ride to the B-level basement, 5 floors below his 4th floor ICU suite.

Late afternoon, an expeditionary force of moving technicians is assembled as Aaron is readied for a trip the CT scanner in the basement. Aaron does not need to leave his wheeled bed for the trip. Some of Aaron's machines will travel with him, and some will be temporarily replaced with more portable versions. Cables are disconnected from the vitals monitor and the numbers of his life appear on a small portable monitor placed at the foot of his bed. His air mattress is detached from the pump and deflates. The Urinator is disconnected. It will stay behind; for the short trip it is not needed. The IV rack is freed from its location and its life lines to Aaron are organized and somewhat untangled. It will be wheeled along with the bed. The bed is jockeyed into position to go through the door. A slim green cylinder of oxygen is laid on the bed next to Aaron. At the very last moment, his line to the ventilator is detached and connected to a clear, plastic bladder the size of a large football between Aaron and the green tank. Aaron's life is now in the hands of the Richard, the respiratory technician who rhythmically squeezes the bladder, breathing on behalf of Aaron's damaged lungs. The flotilla begins to move toward the door.

Just as Aaron's blood pressure begins to drop.

Tiny Kamala, who is directing the operation with quiet efficiency as she keeps glancing at the portable monitor, watches as the numbers of Aaron's life quickly ebb. She does not watch long. The expedition is aborted at the doorway. The Constrictor Norepinephrine, at the ready, is administered. Aaron's vessels obediently constrict, his blood pressure rises. Line by line Aaron is reconnected to his machines.

He regains stability. The rest of the day passes without event.

A damage report is needed. But Aaron is too damaged to get it.

The basement seems like a long ways away.

[5 Comments »](#)

[Please Keep Praying \(by Natalie\)](#)

This is really tough! I'm sure you all realize that! Tomorrow it will be two weeks since Aaron will have been sedated. I miss my best friend. The kids miss their daddy. It is really hard to keep going when seemingly there is so little progress. But I believe that God is at work healing Aaron's body. I don't

know for certain what God's plan for us yet is but I do know what the Bible tells us what we should do. I am still praying in faith that God will heal Aaron for His glory. Jesus is my hope and my strength. I am so thankful for His mercies thus far, in fact I see new mercies every morning...Great is His faithfulness! I covet your prayers. It means so much knowing that so many people are petitioning God on our behalf. I ask you to keep us in your prayers because prayer changes things!

[9 Comments »](#)

## **June 4, 2006**

[Day 20 Sunday, 4 June, 2006](#)

Natalie is the first to observe Aaron's hair falling out en masse. This most cosmetic consequence of chemotherapy will mark Aaron to the world as certainly as his blood counts mark him to the doctors: he is undergoing treatment for cancer.

But our interest is not in the loss of his hair; our interest is in the breath of his life.

After yesterday's aborted expedition to the CT scanner in the B level basement, there is some strategizing as to how the trip might be accomplished.

A test is performed: Leaving all other life lines attached, Aaron is disconnected from the Ventilator and connected to the hand squeezed oxygen bladder. Aaron seems to sense that O'bladder is an imposter...it is not the Ventilator. His dysfunctional relationship with the Ventilator is at least a familiar one.. His pressure drops as before. Some way around this will need to be devised.

Another couple bags of blood and a bag of platelets are given. This time, Aaron's hemoglobin count rises as it should.

Aaron's time with the endotracheal tube is drawing to a close. It has been giving him life for 2 weeks, but like so many life saving measures, it does not come without risk. Long term use of a tube jammed down the throat risks damage. But Aaron's lungs are not ready to breath on their own. His relationship with the ventilator needs to continue. Perhaps it can be made a little less dysfunctional and more tolerable by connecting the Ventilator to a tube through a small hole cut in the throat and directly into the windpipe (trachea) below the larynx. Aaron is scheduled for a tracheotomy tomorrow.

Aaron spends most of the day sedated to a level just below awareness. There is some concern that he should be a little more aware than he is, that he should be a little less compliant with the Ventilator than he is.

[10 Comments »](#)

## **June 5, 2006**

[Day 21 Monday, 5 June, 2006](#)

The ICU on the 4th floor is a round room, it's eight patients like short spokes of a large hubbed wheel, feet facing the hub. There would be 12 spokes, except at opposite sides of the periphery are large double doors through which oscillates the transient community of the ICU. The four spokes on each side of the double doors are enclosed, small rooms with their own doors opening to the hub: the suites. The suites are occupied by those for whom infection is most deadly; those who have no white cells to provide protection against infectious marauders. Twenty-three year old Hector's suite is opposite Aaron's; their feet face each other.

Hector's mother, widowed a year ago and usually these last weeks surrounded by a warm and supportive family, sits alone in the waiting room down the hall from the ICU sobbing quietly. Anne crosses the room, sits beside her, wraps her in arms that know the meaning of sorrow. Hector was

diagnosed with AML in January. Apparently beating the odds at home on leave from the hospital 3 weeks ago, a small infection in his lungs qualified him for his suite a week before Aaron claimed his. The infection did not stay small for long. Hector's mother is told today of the extent of his lung damage.

At about 2 pm, we are shooed from the ICU as the tracheotomy scheduled 3 hours ago is performed. It's a funny thing about medical interventions: they are messy, bloody affairs that the intervenors quite adamantly insist be hidden from those who are the beneficiaries. Aaron must be cleaned and tidied before we are allowed to see the spanking new tube protruding from his throat and connecting him to the Ventilator.

Cleaning for the surgery and tidying up afterwards has claimed most of his beard. No need for a razor; you can get a good shave with a washcloth and a week of poison therapy.

Aaron's suite is too small for the surgeon's portable surgimobile and the Urinator. The Urinator is disconnected. It is taken away, and not returned. Aaron is going on his own.

Still unable to take the elevator trip to the basement, Aaron's abdomen is scanned with a portable ultrasound wheeled into his suite.

Early in the morning, Aaron's sedative was reduced to the point of awareness, and a repeat performance of gagging spasms of last week; blood pressure shooting up to 200, racing heart, breath rate nearly 50. He is quickly returned to deeper sleep, and for the rest of the day he is stable, accepting the tracheostomy without a hitch.

Posted in [Uncategorized](#) | [9 Comments](#) »

**June 6, 2006**

[Day 22 Tuesday, 6 June, 2006](#)

The numbers all say that Aaron continues to improve. He is kept sedated below the level of awareness, but not by much. As testament to his stability, he shares his nurse Akemi with another patient. The Ventilator settings, as do the numbers of Aaron's life, little by little, trend toward normality. The trend is not monotonic; adjustments are made hourly, tweaking oxygen, volume, and pressure (amplitude, frequency, pulse shape, duty cycle). Some hours, the settings advance toward normal, some hours they retreat. It's a slow halting process, not unlike a battle between well-matched armies. At any given moment, the picture can look good or it can look bad.

Yesterday, 3 colorful armbands arrived unannounced at our transient encampment in the 4th floor waiting room. John, Debbie and Ashley from New Leads, Aaron's employer, bear the banded arms, decorated for their contributions to this battle.

Today, a measure of their contributions is utilized as yet another bag of milky, light-gold platelets join forces in Aaron's bloodstream with Aaron's own legions of molecular engineers repairing the devastation wrought in the initial onslaught, now 12 days past.

Our gratitude is beyond measure.

### ***First Time Awake***

**June 7, 2006**

[11 Comments](#) »

[Day 23 Wednesday, 7 June, 2006](#)

On a scale of “Two steps forward, one step back”, today is a 3-step-forward day. The gradual, halting improvements of the last week to which only numbers dared testify blossom today into victories to which even our blissfully lay eyes joyfully testify.

Today, our faith is made sight.

The giver of Aaron’s sleep is withheld after morning rounds, and Aaron begins to awake. Eyes, still swollen and whites bloodshot to solid red, blink, then open. Eyebrows arch in expressive request and in response to questions. Lips move with slight but careful motion; were we adept lip readers we could perhaps understand. Natalie leans close, avows her love, and dissolves in joyful tears as Aaron SMILES! This, we clearly understand.

Pertinent binary questions receive appropriate nods and shakes. Impertinent questions are ignored or dismissed with an eyebrow twitch. Limbs move perceptibly in response to requests. The gagging paroxysms of last week are gone with the endotracheal tube; discomfort and coughing, somewhat harsh, are taken in stride. For 3 hours, the Ventilator allows Aaron’s lungs to work and make all the decisions about how to breathe. The Ventilator provides only assistance, rather than direction. Aaron tires, but does well.

What wonder and what miracle. Shattered, bleeding and bruised, rendered mute for now by the life-giving tracheostomy, vision blurred, body weakened by savage battle, groggy still from powerful opiate, this is unmistakably and wonderfully Aaron.

He comprehends as we tell him of his journey. Anne tells him how near he has been to his sister Celeste, her 11 mortal years having ended 20 years ago. He knows; silent tears flow down his nearly beardless cheeks.

A spiking fever subsides as midnight approaches, and Natalie says goodnight. Aaron mouths a kiss.

This is a very good day indeed.

[5 Comments »](#)

[Praise God! \(by Natalie\)](#)

Praise God! We had a really exciting day here! They reduced the sedation a good deal and Aaron was kind of conscious for most of the day. We’re praising God because, unlike the last time they tried anything like this, Aaron is doing pretty well. They were even able to let him breathe on his own for 3 hours. They started the machine up again but this was really good exercise for his lungs. The most exciting part to me was that he smiled a lot. He gave the biggest smile when I told him about this blog! So, praise God with me for the healing He continues to give.

“Help me, O Lord my God! Oh save me according to your mercy, that they may KNOW that this is Your hand—that you Lord have done it!” Psalm 109:26-27

**June 8, 2006**

[Day 24 Thursday, 8 June, 2006](#)

Today continues yesterday. Good news, and more of it. If we were living in Lake Woebegone, where residents fear too mild a winter might incur Divine notice and the following winter will be extra bitter to even things out, we would be worried. But this is Westwood, where there is no winter. And we have from the start not only welcomed Divine notice, but we have had the audacity to implore Divine scrutiny. It is quite too late to hide.

Aaron did so well yesterday that the CT scan, interminably postponed for 5 days now, is cancelled. (Which goes to show that some things, if ignored, actually will go away.)

Ventilator “weaning” continues, with Aaron doing more of the breathing work. His sedatives (Ativan and Fentanyl) are adjusted up and down, always trending down in this chemical weaning process, seeking the elusive sweet spot between pain and somnolence...between coughing and breathing...between agitation and calm. Weaning...leaving the comfort zone...is not so easy, but it is the path to progress and the way to victory.

Aaron’s eyes not only open, they move slightly from straight ahead. He slowly moves fingers, hands, arms, toes, feet, and legs with purpose and deliberation.

In Aaron’s bone marrow, the stem cells are beginning to recover. 19 days ago, a bone marrow biopsy extracted a sliver of marrow and a chip of bone to assess the enemy and chart the onslaught. Today, another sliver and chip are removed. Tomorrow, the enemy’s position will again be assessed.

[1 Comment »](#)

**June 9, 2006**

[It’s Praise God time again!](#)

Friday

We saw God do a miracle today! When I arrived at 8 a.m., Aaron was in the middle of this horrible coughing fit. Really bad. He was coughing something like 30 times a minute. It was exhausting him. Actually, it was down right exhausting to just watch. The doctors and nurses were at a loss to explain why he was coughing so incessantly. They tried a bunch of things but absolutely nothing helped. The coughing made him shake, made his blood pressure sky high and made him extremely fatigued. He was starting to mouth the words “I can’t do this anymore.” All we could do was pray for him. God knew what was making Aaron cough so badly, no one else did. I prayed that He would make it stop. After 4 HOURS of this coughing, I couldn’t stand it anymore and asked for something to be done, like now. They decided to give him propofol—a sedative that he has been off of for days. This was a step back but anything would be better than what was going on. While the nurse was down the hall getting the medication, a respiratory therapist came in and put Aaron back on the ventilator. (They had taken Aaron off the ventilator and put him just on oxygen hoping that would stop the coughing). The respiratory therapist suctioned Aaron’s trach and inflated the balloon inside. When he did this, Aaron IMMEDIATELY stopped coughing! The nurse got back with the propofol and was floored, “What did you guys do?” I’ll let Ken explain what it was exactly that caused Aaron’s coughing in his post. If you were in that room, you called this a miracle. It was such a dramatic difference. God sent this respiratory therapist in and kept Aaron from having to go back to the propofol. What is also amazing is that while Aaron was tiring a lot from all this exertion, he was oxygenating well. I know my God is in control of all of this. It is awesome to see Him answer our prayers. Keep trusting God and praising Him with me!

“On Him we have set our hope that He will continue to deliver us AS YOU HELP US BY YOUR PRAYERS. Then many will give thanks to God on our behalf for the gracious favor granted us in answer to the prayers of many!” 2 Corinthians 1 :10-11

[6 Comments »](#)

[Day 25 Friday, 9 June, 2006](#)

The coughing began around midnight. As Natalie aptly described, by morning Aaron was becoming exhausted and discouraged. He could barely take 10 breaths between fits of coughing. There was considerable discussion and attempts at resolving suspected culprits, but no success. “Could it be irritation from the trach tube?” we wonder.

The trach tube is a small “L” shaped tube, about the size of a ½ inch copper pipe elbow. One end of the elbow protrudes from the throat. A soft silicon rubber flange around the protruding end is stitched to the skin of the throat to hold it in place, and a band around the neck further secures the flange so this plumbing bypass will stay put. Around the opposite end of the elbow (which goes down the trachea) is a small, inflatable doughnut...like a miniature inner tube. After the trach tube is installed, the doughnut is inflated, forming an airtight seal between the outside of the tube and the inside of the trachea and forcing all the breath going in and out of the lungs to go through the tube and not through the mouth. It also prevents fluid and gunk in the mouth from dripping down the trachea and into the lungs.

A clever design feature of humans and other creatures makes double use of our breath: From “Freude schöner Götterfunken” to “I wanna hold your hand”, our voice is provided as a second thought by our breath on its way out after servicing the lungs. The trach tube, unfortunately, sidetracks the breath, bypassing the upper throat, so the larynx languishes in breathless silence.

However, if the doughnut is deflated, breath may course along its designed path, and voice is possible without removing the tube. When the doughnut is deflated, fluid and gunk as well as breath may course from the mouth down the trachea.

We ask if deflating the balloon might reduce the irritation. Kamala answers from years of experience that it would make things worse. There seemed to be no solution to the coughing.

Then came the angel from Respiration. Suction around the inner tube, inflate to a higher pressure, and voila, the miracle: no more coughing. Kamala was right about the irritation getting worse if the doughnut is deflated....but no one suspected it might not have been not properly inflated in the first place. A question comes to mind: If your car starts coughing, should you check your tire pressure?

As part of the ongoing weaning, Aaron is completely removed from the ventilator for a couple hours; he does well. He spends most of the day resting and not as responsive as the last 2 days.

The pesky fever returns. Anne and Natalie help Awesome Donna (night nurse with oncology experience) help make Aaron comfortable and cool him the old fashioned, and much more effective than the cold-blanket technotrapion, way....wet washcloths.

It works, and by midnight, the fever is gone.

We get no word on the enemy.

[1 Comment »](#)

**June 10, 2006**

[Day 26 Saturday, 10 June, 2006](#)

On the standard “two step forward, one step back” scale, today was a lateral step perpendicular to the scale.

The plan for continued weaning disappear with last night’s fever. Why does this fever keep returning? Aaron has always been sinus challenged. He also has some implants left over from jaw surgery 10 years ago. Both are possible suspected hideouts for festering infection. So a trip to the B-level basement is ordered “Stat” (fancy word for “right away”), where the GE Light Speed CT scanner waits to render it’s damage assessment imagery. (Which just goes to show that some things that appear to go away, really don’t.) The expeditionary force is re-assembled and the flotilla moves down the hall to the east wing elevators, down the elevator to the B level basement, and into the domain Gilbert, who sits in the CT (abbreviation for “Computed Tomography”, which isn’t fancy for anything. CT is an

invention whereby thousands of x-ray pictures made by an X-ray and detector orbiting the patient are deciphered and assembled by a computer into a 3- dimensional image of, for example, the inside of Aaron's head.) control room adjacent to the hulking Light Speed CT scanner. Aaron and his tangle of attendant life lines are shifted by the flotilla crew onto the narrow table pointing like an arrow toward the center the 8-foot diameter doughnut containing the orbiting x-ray. The moving crew leave the room, Suzy and Oded (nurse and respiratory technician) stand in the control room watching the portable vitals monitor at the foot of the narrow table, Gilbert pushes buttons on his control panel and the table moves Aaron's head through the doughnut in incremental steps as image slices of his head form in the computer and about a minute later, on Gilbert's monitor.

Aaron returns to his suite, and is reconnected.

He barely settles in before a neurologist begins a series of tests, which consist mostly of annoying questions and painful pinches. In Aaron's semi-somnambulance and intermittent intersections with reality (at least reality as we perceive it), he is clearly wanting to please his pain-inflicting taskmaster. But when asked to hold out two fingers, Aaron can only manage to slowly lift a feeble hand a little off the bedsheet. He cannot form two fingers, and his determined grimace yields to tears of frustration.

The damage report, confined only to his head since abdominal damage seems now not to be a concern, returns a couple "Stat" hours later. There appears to be a sinus infection.

And some spots in his brain.

The spots demand another "Stat" trip to the basement. This time, Aaron gets a twofer: another CT and an MRI (which is an abbreviation for "magnetic resonance imaging", which used to be called "nuclear magnetic resonance imaging", which is a little more descriptive of the process but the word "nuclear" made people nervous so the marketeers conveniently dropped it).

The results of these damage reports will wait until tomorrow.

The results of the day-before-yesterday's bone marrow biopsy do not wait.

The mutants are back.

[4 Comments »](#)

**June 11, 2006**

[Day 27 Sunday, 11 June, 2006](#)

There is an inexplicable exhaustion that ensues from hanging out with Aaron. Perhaps it is the intensity of his struggle, palpable through the sedatives and opiates, that vicariously saps us. Perhaps is the company of the ICU's transient community, where so much life hangs in the balance so constantly; where the intermittent appearance of an ICU nurse in the waiting room down the hall from the ICU brings a hush to the chatter. ICU nurses do not visit with good news. (Last night, a nurse tells Hector's mother that Hector is having convulsions.) Perhaps it is knowing that today begins the fourth week of an anticipated one week visit to the ICU.

Or perhaps it is our focus.....sharp, singular, and relentless.....the battle for Aaron's life. It is odd that we should tire so, for we are more onlookers than warriors in this battle that is waged at so many levels. From the molecules and cells at war inside Aaron, to the army of experts and machines at UCLA, to the conflict in the ineffable realm of the Sacred, we are but cheerleaders and petitioners at best. But we welcome our small part standing on the sidelines, and we are fortified by those who stand with us.

The spots in Aaron's brain appear to be small hemorrhages, most likely due to his ongoing deficiency of platelets. Dozens of tiny probes with thin protruding wires are taped to Aaron's fast-approaching-bald head, giving him the look of science experiment gone awry. The results of the EEG suggest that the bleeding is benign for now.

A good part of the day is used up changing catheters and various lines as a preemptive strike against infection. The NG tube is removed so as to not aggravate the sinus infection, and an OG tube is inserted

The fever dances its daily on-again off-again jig.

Toward late afternoon and into evening, several hours of coughing, vomiting and diarrhea keep us out of Aaron's room (Nurses don't like us to see this messy side of their job.), give us a focus for immediate concern, and keep at bay the nagging knowledge that the mutants are again growing inside Aaron, and gaining in strength of numbers for another battle in a war that is far from over. We plead that Aaron will gain strength faster.

[4 Comments »](#)

**June 12, 2006**

[Thank You! \(by Natalie\)](#)

Everytime I think about what everyone is doing for us I am completely overwhelmed. I greatly appreciate everyone who is praying. It is a great comfort to know that so many are turning their eyes upon Jesus and trusting Him with Aaron's health. I appreciate everyone who keeps up with what is going on with Aaron by being a part of this blog. I am grateful for everyone who drives all the way out here to visit even though it is a long drive and the traffic can be frustrating. Each visitor has been a great encouragement to us. Thank you so much to those of you who have donated platelets—what an incredible thing to do! So many of you have sent cards, called on the phone, brought snacks/dinner, donated money and offered help. There is also an enormous amount of people doing HUGE, specific things that are unbelievably generous. In fact, I know that we are not even aware of everyone who is helping us out or things that are being done. From the entire Boydston Family, thank you from the bottom of our hearts. It is so wonderful to tell Aaron, in his half awake state, that he doesn't need to worry about anything—there are so many people helping to take care of all the details. We have truly been blessed by God to have each of you as friends and family.

Above all, I would like to publicly give thanks to God for all He is doing in our lives and your lives, as well. He has proved Himself worthy of our trust. My faith and reliance on Him has been strengthened in this trial. I continue to see His hand in this entire situation and I know He is controlling everything. This week I am especially thankful that God has protected Aaron's brain. You know, for a couple of days there, the doctors were suggesting that the stuff they found from the CT scans and MRI could be lymphoma. We were praising God big time this week when we found out it was only minor bleeding.

So, I'll close with another huge THANK YOU for all that you are doing and continuing to do. Don't forget to keep praying for Aaron! :)

[4 Comments »](#)

[Day 28 Monday, 12 June, 2006](#)

A pattern is emerging over the last few days: Aaron sleeps peacefully, with the numbers of his life in reasonable bounds. (Except the cursed dancing fever that taunts us with its daily jig). The Ventilator's



service is now perfunctory. It's life-giving sophistication is not much required; a little extra oxygen and pressure is about all Aaron needs to breathe well.

Then the giver of sleep is reduced, and Aaron begins to awake. The more aware he becomes, the more he coughs. Perhaps the cough is triggered by the trach tube worrying his trachea. Or it may be the mucous font that seems to be gushing more freely these last couple days. Neither local application of numbing Lidocaine nor the miracle of trachea-suction/doughnut-inflation seems to stop the coughing. Then the vomiting starts and Aaron cleaned and mercifully returned to his peaceful slumber.

Is this a weird Catch-22? Must have the trach to awake, but cannot awake with the trach?

We shall see if tomorrow brings a solution.

We shall also see if it reveals a strategy for the coming battle, about which we learn nothing today.

[5 Comments »](#)

**June 13, 2006**

[Day 29 Tuesday, 13 June, 2006](#)

Today starts with the familiar pattern: sleep, awake, cough, vomit, back to sleep. Coughing strong enough to sprinkle the inside of the translucent corrugated oxygen tube with blood. (Blood: In the real world, blood is supposed to stay tucked away inside the veins of one's body or carefully hidden from view in a monthly exercise of female discretion. The sight of blood outside the body makes the squeamish stomach churn. In the ICU, blood is everywhere: dried, fresh, venous, arterial, puddled, sopping, dripping and squirting. What doesn't erupt on its own or in conjunction with ever so much piercing, poking, slicing and stitching is drawn from veins and arteries like money from an account with perpetual overdraft protection. The sight of blood is so common, a little sprinkled inside the breathing tube doesn't seem like such a big deal. And it probably isn't.)

It occurs to the doctors at morning rounds that a cough suppressant might be worth trying. The savior of many a miserable soul trapped in the hacking clutches of bronchitis is prescribed and later administered: Codeine. Unfortunately, Aaron is sharing his nurse Suzy with a more demanding client, so she doesn't have the time to reduce the giver of sleep and monitor the codeine's effect. By late evening, Anne and Natalie convince the night nurse to reduce the Propofol enough to let Aaron really wake up. He does, and he is awake enough to play the ICU version of "20 questions"... "Are you in pain?" "Shake." "Are you uncomfortable?" "Shake." "Do you want to be suctioned?" "Nod." (In the ICU, clear plastic canisters fill constantly with bloody phlegm from vacuum lines whose sucking tips are regularly being threaded into lungs and poked into noses and mouths and throats that cannot blow, sniff, spit or swallow.)

Aaron deliberately performs leg and arm lifts. He's getting in shape. He begins to cough, but he is awake enough now to suppress the cough and keep it in check by force of will. He repeatedly lifts his left arm (his right arm is still tangled in tubes and probes), each time a little higher, angling toward the trach tube/oxygen supply tube coupling. "Do you want to take out the tube?" "Nod." Anne and Natalie are alarmed. He touches the coupling with his index finger and smiles. He got 'em.

[3 Comments »](#)

**June 14, 2006**

[Day 30 Wednesday, 14 June, 2006](#)

Aaron has found a sweet spot. His giver of sleep is reduced to the point that he is awake enough to participate in his recovery and still not be in pain. Very frequent suctioning by Anne and Natalie and

conscious control by Aaron keep the coughing under control. Aaron would like to suction his throat himself, but he's not able yet to do so. A trembling left hand can reach his face momentarily, but falls back quickly to the bed.

Aaron is doing all the breathing work himself, supported only by extra pressure and oxygen. As a test, the pressure is reduced for a while to a lower level before returning higher. It appears that he passes the test. As the day proceeds, the work of breathing seems to tire him, but his numbers stay good and he remains in touch by discernable nods and shakes.

Less than 3 weeks ago Aaron's white cell count was zero. As the poisons finished and were flushed, white cell production began again, deep in the bone marrow where there still lurk mutant stem cells. For the last few days, the white cell count has been noticeably doubling nearly every day. Exponential growth rates may be quite normal....up to a point. Today, there are about 11,000 white cells in every microliter of Aaron's blood. Though twenty time lower than it was a month and a few bags of poison ago, this is on the high side of normal. If these are bona fide white cells and if they are here to fight Aaron's sinus infection and keep other infections at bay, we laud them...they are our allies. But if they are mutants, we curse them.

Should we laud or should we curse? The answer resides in memory cells of the UCLA Medical Center's on-line medical records computer system. For lack of a password or a convenient doctor (doctors and questions we have for them never seem to be simultaneously available. While the rest of the world has discovered TCP/IP as a means to effective yet non-simultaneous communication, doctor/patient-family communication seems decidedly last century), we not know. Perhaps tomorrow.

The dancing fever continues to vex.

[2 Comments »](#)

**June 15, 2006**

[Day 31 Thursday, 15 June, 2006](#)

Hector died today.

[8 Comments »](#)

**June 16, 2006**

[Day 32 Friday, 16 June, 2006](#)

Theoden king of Rohan said it in the movie awkwardly but well, "No parent should have to bury their child"

No preparation can ready the heart of a parent for the death of a child. Bands of anguish constrict the chest like steel strapping. The heart aches not from bittersweet memory, but from the crushing boa constrictor of grief. There is but one desire, one overwhelming and unfulfillable plea; that the parent's life might be exchanged for the child's. We ache for Hector's mother.

We finally hear from Dr. Paquette that Aaron's white cells, having multiplied exponentially for the last few days to over 20,000, are bona fide. They are our allies. They fight with us against the enemy; we laud them and give thanks. Their numbers are testament to the defensive battle they wage inside Aaron.

Aaron spends all day weaned from the ventilator. A little extra oxygen and no extra pressure work just fine.

Anne reads to him from “Princess Bride” for much of the day. The reading is interrupted by intermittent coughing fits and trembling fits. The trembling fits look like panic attacks: Eyes sometimes wide and terrified, various limbs shake with involuntary tremor. Perhaps it is panic. The survival drug of overstressed middle class America is prescribed: Vallium

Aaron inflates the concept of twenty questions to 26; he gets Natalie to spell “Turn”....Turn down the bed.

More searching for the source of the fever reveals new developments. Leukemic blood, while often low in platelets and not clotting where it ought, sometime clots where it ought not: there is a clot near the top of Aaron’s right leg. Because of the bleeding in his brain and the whole platelet issue, he cannot be given thinners. A clot catcher will be installed in the inferior vena cava to make sure clots in the lower extremities do not find their fatal way to the heart or brain.

It appears that the gall bladder may be badly infected. There is discussion of extraction or drainage. No decisions are made.

[3 Comments »](#)

**June 17, 2006**

[Day 33 Saturday, 17 June, 2006](#)

Of the 11,000 new cases of Acute Myelogenous Leukemia each year in the US, most are grandparents who will be missed by friends, siblings, children, and grandchildren within a couple years of diagnosis. Few will be missed by parents. Only about 100 are young adults like Hector, Eric, and Aaron. Eric, also in his 20’s, was issued his ticket to the 4th floor ICU a couple weeks ago by a lung infection. The invaders of Eric’s lungs are not bacteria. They are fungus who’s rent-free squatting in the air conditioning unit at his home might have gone unnoticed for years by legal residents with functional immune systems. But Eric’s defenses were demolished by the powerful poisons and radiation given to destroy his bone marrow and his ability to reject stem cells harvested from the blood of a stranger in Germany identified by an international computer database of potential donors. Fungus infections are hard to fight. That he yet lives is due to transfusions of white blood cells from his mother, which fight on behalf of his own decimated defenses.

Aaron’s white cell count has leveled off at about 30,000, the high end of a normal response to bad infection. While the search for infection continues, it is the clot in his right external iliac vein that is most immediately worrisome. On the theory that if there’s one, there may be more, and on the knowledge that, for reasons unknown, clots which can break loose and wreak havoc to the heart and lung usually come from the legs, it is deemed important to install a clot catcher in the inferior vena cava so that any clot detaching from either leg will be stopped on its way to the heart. Through a small incision above his left thigh, a tiny, wispy titanium daddy longlegs spider kind of kind creature is inserted and threaded up to the vena cava. There, it is opened like a miniature cocktail umbrella. Its spidery feet brace against the walls of the vein. It will not allow any chunk of stuff big enough to cause damage to pass. While it is possible to remove the catcher, it is also possible that it may never be removed. Just another small uncertainty of the future.

With the clot catcher in place, it is now time to confirm or disprove the suspicions about the gall bladder. The gallbladder is a small, pear-shaped bladder whose purpose in life is to receive, concentrate, and store a few tablespoons of bile manufactured by the liver. An Inuit whose dietary habit consists primarily of gorging on whale blubber might find the gallbladder useful, since bile is needed to digest fat and the liver manufactures bile only so fast. But for most of us, it’s an optional feature with little market value.

Aaron is wheeled for his second field trip (it's no big deal anymore) of the day down to the "A" level basement into the department with the ominous name "Nuclear Medicine". A scintillation detector the size of a fat swamp buggy tire attached to a movable arm is positioned a few inches above Aaron, centered on his invisible liver. It is big enough to nearly touch his chin. A slender box that might be a gift box for an expensive necklace is brought into the room. Except this box is made of lead, and in it is a syringe containing radioactive metastable Technetium 99 (gamma emitter, half-life of 6 hours) which is injected into Aaron's bloodstream. The Technetium finds its way to his liver, and Aaron's radioactive liver now glows brightly on the monitor attached to the detector. Every minute or so, a new image is captured and saved to an ancient (pre-GS3) Mac (one of the few in this decidedly non-Mac environment). In a normal healthy person, part of the glowing liver will fade over the space of an hour as the radioactive Technetium moves with bile produced by the liver into and through the gallbladder.

Aaron's whole liver stays bright for an hour and a half. Something is definitely wrong. The bile is going nowhere. Surgery to remove the gall bladder is scheduled for tomorrow morning. Perhaps this will put an end to the fever's continuing daily dance and the growing pain on the right side of Aaron's stomach; pain enough to part the opiate veil. Natalie wonders if the continuing periodic tremors are perhaps not withdrawal or panic, but pain.

Cousin Kandice, fresh out of fourth grade and into summer, visiting from Santa Barbara, asks her mom if God is married. (Mom's know about these kinds of things.) Tami replies, deferring to orthodox theology, and Kandice observes wisely that she didn't think so, as Mrs. God would never have allowed this to happen to Aaron.

[3 Comments »](#)

## ***Father's Day: Gallbladder Removed and Aaron Speaks***

**June 18, 2006**

[Day 34 Sunday, 18 June, 2006](#)

Natalie decrees that Father's Day be postponed until further notice. We'll wait for Aaron to give the notice.

Dr. Kim comes by early and talks to Aaron. She takes his hand in hers and asks him to squeeze if he is in pain. He does. She asks him where he hurts, and he, with slow and trembling certainty, guides her hand to his lower right abdomen....right on top of the gallbladder. She asks if he wants more pain medication. He mouths "More."

Aaron and his blocked, inflamed, and necrotic (fancy word for "dead") gallbladder part company about the time most congregations are listening to sermons honoring fathers.

A few hours post op, Aaron is coming around and is intermittently awake, always nodding to "are you in pain?" Shots of Dilaudid keep things under control. Aaron is moving more than he has since the beginning of ICU. His nurse Jen [the Bomb] suggests it might be time to try the trach talker. A one way valve placed in the opening of the trach tube that allows air in but not out, together with a deflated trach doughnut (cuff), allows air to be sucked in through the tube and then to pass by the vocal chords on the way out of the lungs. Richard from respiration suctions top and bottom (mouth and lungs) deflates the doughnut, plugs in the talker, and asks Aaron to say "Hello". Aaron tries, only gurgles. Richard says good, just needs more suction, which he applies. Then again "Aaron, can you say 'hello'?" Gurgling and ultra slow-mo but distinctly comes "HHHHHHHEEEEEELLLLLLLOOOOO" Aaron has spoken his first audible word in a month. We are elated. Immediately, he starts another ...

May 16, 2006 – July 3, 2006

“PPPPPPAAAAAAIIIIII...” Whether or not it was “pain” we cannot be sure, as he fell asleep before he finished. The test is a great success. The talker is removed.

Toward evening, Aaron is uncomfortable. He is moving by himself more than he has in a month. He turns completely on his side without assistance. This is a good sign.

Aaron’s heart rate is irregular and goes up dramatically when he moves around. Natalie keeps telling him to settle down and relax. At about 11 pm, Natalie tells Aaron one last time to relax and be still. Aaron grabs a handy washcloth and smacks her repeatedly. Then he mouths kisses. This is a very good sign.

The gallbladder is the most likely suspect so far as the source of the taunting fever. We hope that its departure will hasten our belated Father’s Day celebration, when Michaela and Christopher get to give dad the hugs and kisses denied for over a month now by the enemy’s cruel interdiction.

[2 Comments »](#)

**June 19, 2006**

[Day 35 Monday, 19 June, 2006 a.m.](#)

Anne sits with Aaron through a restless night, during which the ventilator was reconnected to give his lungs a rest. His breathing is much improved over the last few days; nearly normal, large volumes and good respiration at about 15 breaths/minute.

By early morning, Aaron is off the ventilator and back to just oxygen. Natalie is playing 20+ questions. Aaron really wants something. Finally, “Do you want to sit up?” “Nod.” Natalie puts in a request, and the Chair is wheeled into Aaron’s suite little before 9:00 am. Unlike coach airline seats which make a mockery of the word “recline”, The Chair reclines to totally flat, allowing Aaron to be slid from his bed to The Chair before sitting him upright. He is strapped in and The Chair moves him to a slightly reclined sitting position. He sits the rest of the way up by himself. He smiles and rocks forward and backward, exercising his torso. “Do you want to talk?” Vigorous “Nod.”

He is suctioned top and bottom. Suctioning the lungs fills the suction tube and produces vigorous coughing, which sprays bloody gunk through the trach tube and around the room. Unlike the coughing of previous days, this coughing is useful. It rids him of gunk and makes him feel better.

The talker valve is placed in the trach tube and Aaron immediately, clearly, without gurgle, in a thin, tremulous, singsong tenor voice, says “Hello.” And then “I can talk! I can talk! I can talk! It’s been so long since I’ve been able to talk.” His eyes, still bloodshot and popped impossibly open to several saucers past “wide-eyed”, sparkle.

The ICU doctor team is making rounds as Aaron sits facing the door of his suite and the team standing outside the door. He smiles at them and moves his hands in applause. “Thank you.” The doctors beam as they seldom do in the ICU. They are winning this round, and they know it.

[7 Comments »](#)

[Day 35 Monday, 19 June, 2006 p.m.](#)

While still sitting in The Chair, Aaron broaches the subject of walking. He’s quite certain he is ready. George (nurse today) calls Physical Therapy and tells Aaron that Physical Therapy will come to help with the walking. For the rest of the day, when not hallucinating, getting Physical Therapy is Aaron’s constant theme and consuming focus. “Are they on the way? Are they here yet? When are they coming? I’m ready to walk. I’ve got to get out of here. I’m ready to go home. Mom, let’s go home. Get

me out of here. They are holding me here and not giving me water. Is Physical Therapy coming? I have no pain.....let's go for a walk."

He offers \$200 to get them here now. When told they are busy, he ups the offer to \$300. He tries to borrow money from one of the doctors for the payoff to Physical Therapy. He promises Mom that he will spend no money if she will take him home. Wheeling and dealing, persistent and focused, Aaron is true to form, though the form is a tad cracked.

Aaron is ready for bed after a half hour in The Chair. In bed, he fidgets, tosses, and turns all day, getting ready to walk with Physical Therapy and hallucinating. The hallucinations would be funny if they weren't so wearing. Natalie and Anne spend hours closing imaginary drawers which contain pieces of Little Red Riding Hood. Natalie is Zorro, tracing Z's on Aaron's chest and fighting evil.

Did someone substitute a mixture of methamphetamines and LSD for the Valium? George thinks the Valium might not be having its expected effect, so he stops it. By evening, Aaron is more lucid. He asks for The Chair again. When the 20 minute operation to get him off the bed and into The Chair is complete and he is sitting nicely, Natalie asks how it is. "Anticlimactic," is his single word reply, pretty much summing up this afternoon.

He tires after a while, is returned to bed, and falls to a quiet sleep, his first since that which came by way of the anesthesiologist at yesterday morning's surgery.

Aaron and Eric (who has improved slightly over the last few days) are the youngest residents of the ICU. They have also been there the longest.

The eight patient spokes do not stay empty for long. The ICU seems to have an effective JIT order system for new patients. The names written on the patient/nurse/doctor assignment whiteboard change daily, and empty spokes are filled within hours. There is little discussion about those who leave. But when we are in Aaron's room and we are asked to shut the door for 5 minutes, we know that in one of the spokes the doctors did not win, and another family will grieve.

And yet we believe that for Aaron, Father's Day is coming soon.

[5 Comments »](#)

**June 20, 2006**

[Day 36 Tuesday, 20 June, 2006](#)

Physical Therapy finally arrives this morning. They do not disappoint. Aaron sits in a regular chair, with his feet on the ground. He is helped to his feet, and with support, stands. He is elated. Physical Therapy had intended a passel of beginner movements which they scrap, as he is so advanced. The work done by Anne and Natalie moving his fingers, hands, arms, feet, and legs when he could not, and Aaron's own leg lifts and arm lifts while he was still in bed and barely conscious have paid off.

By late afternoon, Aaron is ready to go at it again.

His white blood count, which had stalled for a couple days at about 30,000, doubled again to 60,000 before retreating slightly. The count is nearing danger territory. We had hoped that the infernal fever, together with the elevated white cell count, would have departed with the evicted gallbladder. Neither shows any sign vacating.

[6 Comments »](#)

***Out of the ICU***

**June 21, 2006**

[Day 37 Wednesday, 21 June, 2006](#)

The ICU is where you live if you can't live anywhere else. You don't choose to go there, don't choose how long you stay there, and you don't choose which way you leave there. The front double doors of the 4th floor ICU open to the West Wing corridor. Through them, patients, visitors and staff flow back and forth in the irregular rhythms of ICU life. The back double doors open to eternity; transport teams push covered gurneys through them on their way to the morgue.

Today, Aaron left through the front double doors to take up residence at room 1041 in the West Wing on the 10th floor of the UCLA Medical Center. He is well enough to live outside the ICU.

The 10th floor is the last elevator stop up. Through north facing windows we overlook the UCLA campus and can see to the west the Getty museum, where some of the world's finest tableaus of life hang on walls and are perused by admiring patrons. Here in the Medical Center, dramatic tableaus unfold daily as involuntary denizens are subsumed into them, and consumed by them.

The 10th floor is an "All Suites" floor. Cancer patients do not share rooms. Doors are always closed; the corridor is usually empty. Infection is the enemy's most persistent, pervasive, and deadly ally; isolation is a key defensive tactic.

Natalie noticed day before yesterday that Aaron's upper right chest was swollen. An ultrasound scan revealed no clotting. Yesterday, a multitap (like an octopus of tubes) IV line which penetrated the swollen area was removed on suspicion of infection. Today, his white count drops to 30,000, and for the first time in over a month, the fever does not perform its daily dance.

Aaron is mostly lucid. (Yesterday morning he announced that he had fixed a number of bugs in the hospital computer system.) When he moves his hands, they tremble like hands whose owners are inflicted with advanced Parkinson's disease. He talks only a little before tiring. The talker valve restricts airflow enough that it makes breathing harder; he wants it out most of the time. He is helped to sit up again for a short while.

He does not like to be left alone. He understands that he cannot fix problems, cannot operate the bed controls, cannot operate the call button, cannot summon help. In the ICU, attention is close and constant. The 10th floor by comparison seems deserted. A visitor's cot is brought in for overnight stays. Isolation is tempered so it does not become desolation. Room 1041 feels almost homey.

[7 Comments »](#)

**June 22, 2006**

[Day 38 Thursday, 22 June, 2006](#)

To watch Aaron's body heal is to see the hand of God. Restoration is a sort of caffeinated creation. Complex and interrelated systems, laid waste by the enemy, play leapfrog toward unity and wholeness. Two weeks ago, progress was decoded by arcane numerology. Today, progress doesn't need decoding; it demands rejoicing.

Yesterday, Aaron could sit up with much assistance. This morning, he could sit up with moderate assistance. Tonight, sits up by himself. This morning he could not operate the call button; tonight he can operate the button and call for help. The thin and tenuous voice of yesterday deepens and solidifies today. The trembling is diminished noticeably from yesterday; Aaron can hold a cup in his hands.

This morning, a flexible bundle of optical fibers is shoved up Aaron's nose and through the nostril to where it enters the throat. Lights, camera, action: Aaron's throat is live on a TV monitor as he

samples different viscosities of green goop to check his swallow response. It is determined that he can swallow liquids between the consistency of a peach smoothie and a chocolate shake. Small packets of cornstarch are provided to thicken liquids of choice. Aaron's first choice, appropriately thickened and downed a few hours later: Kiwi Strawberry Snapple.

Another bone marrow biopsy is scheduled for tomorrow.

[6 Comments »](#)

**June 23, 2006**

[Good and Bad \(by Natalie\)](#)

I have been trying to sneak away from Aaron for quite some time now in order to write a post but he keeps us very, very busy. We make sure that he is not left alone even for a minute because he isn't able to get anything for himself yet or even call for help. It has been a wonderful week full of God's protection, provisions and miracles. It was very shocking to hear at rounds yesterday the first mention of Aaron being well enough to leave the MICU. It was even more shocking when we got the boot just a few hours later. I became quite spoiled in the MICU with having a nurse, respiratory therapist and several doctors right outside the door all day long! 10th floor life is very different.

Just in case there are some of you who are unaware, Pastor Lyn Thomas is writing a summary of what happens with Aaron each day on our church's website, [www.ojaiwesleyan.org](http://www.ojaiwesleyan.org).

We are so blessed to be supported in prayer by you all. I have seen so many amazing things in the last week that I give God total credit for. He is answering our prayers! It is also a blessing to hear from so many people. Every card, note, phone call and visit are treasured. We check for comments on this blog regularly and are always thrilled to read what you have to say, especially those of you who we haven't communicated with in a long time! Feel free to call or visit anytime.

I continue to have nothing but praise for God. He is good all the time. I've been learning the importance of praising God in trials as well as when things are "going well." It is easy to praise God for good things but when things look "bad," I find that this is when it is most important to praise and worship Him. Also, I am realizing that relying on God and turning to Him when things look "bad" seems to come naturally. But I want to come to Him with the same fervency and dependance when things seem "good." I am trying to keep my faith in Jesus and not whether things seem "good" or "bad" according to doctor reports or how Aaron looks. There is an awesome peace and joy that God gives when you just simply trust Him and you don't base how you feel on what the circumstances seem like at any given moment. My eyes are continually on the Lord!

Matt Redman - You Never Let Go

From the album Passion 06: Everything Glorious

Even though I walk through the valley of the shadow of death  
Your perfect love is casting out fear  
And even when I'm caught in the middle of the storms of this life  
I won't turn back, I know You are near

And I will fear no evil, For my God is with me  
And if my God is with me, Whom then shall I fear?  
Whom then shall I fear?

Chorus:

Oh no, You never let go  
Through the calm and through the storm



May 16, 2006 – July 3, 2006

Oh no, You never let go  
In every high and every low  
Oh no, You never let go  
Lord, You never let go of me

I can see a light that is coming for the heart that holds on  
And there will be an end to these troubles  
But until that day comes  
Still I will praise You, still I will praise You

[4 Comments »](#)

[Day 39 Friday, 23 June, 2006](#)

John Wyndham, brilliant sci-fi author whose stories became classic B movies, writes of change....Sudden, unexpected, dramatic, rhythm-arresting, life-altering change.....and how we react to it. Aaron's cancer is such a change. For Aaron, the change is profound. Even his most basic biological rhythms of metabolism were arrested, and his rhythms became those imposed upon him by his caregivers and his attendant machines.

For close family and friends, the change is vastly less, yet consuming. For us, the altered rhythms are not so much in the biology of our bodies as in the liturgy of our lives. Jobs, showers, school, sleep, dressing, bills, church, haircuts, laundry, sports, root canals, meals, and anniversaries (Natalie's parents are married 35 years this week, Aaron's 33) do not cease. But they are altered, disrupted, and displaced. And as our wider community surrounds us to share the burden of these displacements, we are blessed beyond measure and filled with gratitude.

Aaron keeps improving. He sits up several times.

He gets yet another trip to the B level basement for a CT scan (head only) and yet another painful bone marrow biopsy. He coughs more, but is fine with minimal oxygen assist.

[1 Comment »](#)

**June 24, 2006**

[Day 40 Saturday, 24 June, 2006](#)

40 days and 40 nights. It seems that for now, the rain has stopped. When the waters will recede, and when our dove will return with an olive branch, we do not know. At least we aren't cooped up in a prototype ark with pooping elephants.

Yesterday's CT scan shows no new bleeding in Aaron's brain. We hear nothing of the findings from the scouting foray into the enemy's bone marrow camp.

Aaron sits up and motions for the laptop; he goes on-line. (Wi-fi is thankfully available, though spotty.) He wants to edit the blog. He can read 12 point Times New Roman at 150%. (A week ago, he could not read at all.) The keyboard is still challenging. He tires after a few minutes, and must lie back down.

Web-guru/gaming-buddy Nathan first connects a VCR, then rigs the Xbox to further pervert the hospital room TV. Aaron's not up to playing, but watches and pantomimes along with the first few scenes of "Fellowship of the Ring".

The L.A. film festival has been going on for several days. Westwood village, with a dozen theaters 10 minutes walk from the room 1041, plays host and premieres "Superman Returns". In Room 1041, the real superman is returning.

[2 Comments »](#)

**June 25, 2006**

[Day 41 Sunday, 25 June, 2006](#)

Hospitals have CODES. Codes for nearly everything; fancy word codes, acronym codes, letter codes, number codes, and color codes. The main purpose of the codes is to confuse and prevent the hapless layperson from knowing what the heck is going on. But hapless laypersons, thanks to TV scriptwriters, eventually figure out some codes, like “CODE BLUE”. The PA system blaring “Code Blue...Code Blue...Code Blue” might just as well be saying “Help! Help! Help! Someone is about to die and we have to do something right away but we don’t know what to do, so everybody come running and mill around and do stuff.”

Early this morning, Natalie is quietly sitting alone with Aaron, when through the 1041 door, past Rosemarie’s big “Smile Required for Entry” poster, past Natalie’s “This sickness is not to end in death, but for the Glory of God...” poster, in rush the nurse gendarmes, responding to “CODE GRAY”; “ABUSIVE PERSON OR PERSON WITH A WEAPON”. Now how did they know? There is, in each room, a CCTV camera disabled by a bit of misguided congressional wisdom known as HIPAA. Aaron doesn’t have a vitals monitor, it having been disconnected a couple days ago (as he has out-improved its usefulness!). Beeping IV line monitors are pretty much ignored. So how did they know the goings-on behind the closed door of 1041? Can remote medical diagnostics now detect abusive qualities buried deeply in the psyche? And finally the real question, “Was it Natalie or was it Aaron?”

Sunday doesn’t quite blend into the other days of the week. Non-critical lab results are not available (including the results of Friday’s bone marrow biopsy), the elevator ride from the first to the tenth floor is more likely to be an express, and visitors come bearing munchies and distraction. This is the first Sunday that Aaron can appreciate the distraction, if only for a few minutes at a time.

His coughing has worsened, and it is with effort that he tries not to cough. Robitussin and Codeine are tried without seeming effect. Dilaudid seems to be the most effective cough suppressant; it’s suppression is administered by way of sleep, so Aaron is not too sociable. Though when he is awake, he is unfailingly polite; always “please” and “thank you”. The neatly stapled-shut incision from the gallbladder removal oozes blood and the drain line from the abdomen seems to drip bile unabated into a fist sized bladder that keeps getting in the way. Perhaps the coughing has loosed up the otherwise tidy and healing-nicely incision. Yet another CT scan is scheduled to check for the source of the cough.... Pneumonia is, as always, suspect.

Down the hall, Eric is also doing better...he was kicked upstairs from the ICU a couple days before Aaron. His fiancée April describes how, having achieved remission, he ignored for several years the strong recommendations of the doctors to obtain follow-up treatments. A few months ago, in lieu of the follow-up treatments, began the relapse and its nearly fatal consequences.

The first day of summer has come and gone, nearly unnoticed. It is comforting that the rhythms of the seasons are immune to our displacements.

[3 Comments »](#)

**June 26, 2006**

[Day 42 Monday, 26 June, 2006](#)

Ignorance may be bliss, unless it’s ignorance about the results of a test that should be available but are not, like the results of Friday’s bone marrow biopsy, about which we are as ignorant today as we were yesterday.

We are slightly less ignorant about the results of yesterday's CT scan. The scan neither confirmed nor disproved pneumonia. It did confirm, however, some fibrosis (fancy medical word for "Scarring") of the lungs. Fibrosis is permanent damage that is a consequence of the carnage that occurred immediately before and during the Onslaught.

Aaron's cough is about the same. He is helped to standing several times today. He swallows capsules of Tessalon Pearls, another attempt at suppressing the cough. After the initial novelty of drinking a couple days ago, drinking is of only moderate interest.

Like a forest after a fire, Aaron's hair, which never fully fell out, now shows signs of re-growth.

[1 Comment »](#)

## ***Remission***

**June 27, 2006**

[SMITE! \(by Natalie\)](#)

"...ye shall know that I am the Lord that smiteth!" Ezekiel 7:9

Ever since the bone marrow results came back positive for leukemic cells (after Aaron's first round of chemo), I have devoted myself to praying about these cells. When the results came back, there was a natural tendency to look at this as a negative situation. But the thing I keep learning about faith is that no matter what things look like, we are to keep trusting God. Since those results came back, I have worked at keeping my faith in God by CONSTANTLY squashing every discouraging, doubtful or negative thought that comes into my mind regarding Aaron's leukemia and replacing those thoughts with truths from God's Word about who God is and what He desires from us and for us. I have reminded myself that those results could be completely wrong, changed immediately by God or used for Aaron's protection in some way that is not obvious right now. As I have put my trust in God concerning the leukemia that remained in his bone marrow, I thought of the word "smite." I thought this word not only fit in well with Dad's description of the cancer as a battle but I thought it was a good King James word, too. I began to pray that God would smite the leukemia in Aaron's bone marrow. Everyday, all day long, for the last couple of weeks this has been my cry to God. My good friends, Lisa and Nathan, have been praying for this smiting, as well. It was one of the best things in the world to get to make the "smite call" this morning to Lisa. In fact, she answered the phone by saying, "Is this the smite call?" We absolutely had faith that God would smite these leukemic cells in the marrow. We just waited on God's timing. Well, now the leukemic cells are gone from Aaron's bone marrow and I give absolute praise to God for this. It was not the doctors, it was not the medicine, it was God that removed the leukemic cells. I am very grateful for all of the doctors, nurses, medicine, technology, etc. that God has used thus far but I recognize that it is God that decided to remove the leukemic cells. Please, continue to pray with me. First of all, praise God for what He has done! Secondly, ask and believe that God will continue to bring complete healing for my husband. God has been faithful so far, there is no reason to doubt Him.

[5 Comments »](#)

[Day 43 Tuesday, 27 June, 2006](#)

Aaron is in remission!

The dove who delivered this olive branch walked into room 1041 a bit before noon wearing a white coat and a badge with the name of Dr. Norma Bucher. Friday's bone marrow biopsy shows no trace of the enemy. The enemy bastions seen in the biopsy performed 19 days ago (14 days following the

Onslaught) were alive, but reeling. Their attempt to regroup failed; as the army of the ICU were marshaling their medicines and machines and restoring Aaron's life, the last detectable traces of the enemy were being destroyed. Sweet Natalie's smiting imprecations, together with those of all the saints, put God in a smiting mood, and He smote. Do not be an enemy of Natalie's lover. Hell may have no fury like that of a woman scorned, but Heaven smites for Natalie.

Remission does not mean that Aaron is finished with treatment. AML is a wily enemy. It hides within the marrow in molecular nooks and crannies as yet undetectable. While no cells express detectable cancer markers, experience has shown that, if no further campaigns are mounted, the cancer will very likely return within a few months; Aaron would then relapse, and the enemy would again hold sway.

Thus, mop-up campaigns, known as "consolidation", will begin as soon as Aaron has the strength to endure another round of poisons, aimed to root the unseen enemy from its undetectable hideouts.

Aaron's strength and dexterity continues to improve, though his left arm is partially immobilized by painful tingling and numbness. Just above the left elbow is the insertion point for the IV PICC line. Perhaps it is responsible.

The cough is better today. Dilaudid dosage is reduced with good effect. A small fever comes but never gets traction.

Aaron can operate the bed, use tissues, wipe his face, brush his teeth, drink from a cup, talk on the phone (he talked to Michaela and Christopher today!), and sit up on his own

With Aaron sitting on the edge of his bed, a standing partner faces him. Partner bends knees, wraps arms around Aaron's back and Aaron wraps arms around partner's neck. Aaron stands, steadied and supported by the partner. In close dance position, Aaron and partner (happens to be dad) shuffle 3 small steps away from the bed and 3 steps back. Aaron's first steps are a waltz. Music need not be played. It's ringing from the heavens.

[19 Comments »](#)

**June 28, 2006**

[Day 44 Wednesday, 28 June, 2006](#)

Aaron's left arm is a little worse today...tingling, numb, and painful. Looks like ultrasound scan and MRI are forthcoming.

Another swallow test is performed....Aaron's tonsils perform on live TV. The performance is excellent, so Aaron is given the green light to eat anything he wants. (Probably the dietician is not aware of his penchant for Tobasco.) He eats a slice of chicken quesadilla (mild, for a change). He sits up for a couple hours, and leaves the trach valve in his trach for longer periods of time. Tomorrow, Christopher will turn 3 years old.

**June 29, 2006**

[Day 45 Thursday, 29 June, 2006](#)

Superman party in room 1041! This gala celebration of Christopher's 3rd birthday is the first opportunity for Christopher and Michaela to see dad since pre-ICU days. Grandpa Metz dons a red cape, billowing in the sanitary breeze of the HEPA filter. Michaela holds dad's hand and says he looks really handsome. Christopher doesn't want to wear the face mask (so Aaron puts one on) and digs in to a superman chocolate cake like nothing was out of the ordinary at all.

The ultrasound scan of the tingly left arm reveals a small clot but nothing to account for the numbness, so an MRI is scheduled. Prior to the MRI, the IV lines are disconnected. By the end of the scan, Aaron realizes that the arm is suddenly functional. The main purpose of the disconnected IV was to supply food. Now that Aaron can eat, the decision is easy: Leave the line out.

Aaron stands up on his own and takes 3 real steps without help.

There is discussion that Aaron may go home for a short break before the next round of poison begins.

[6 Comments »](#)

**June 30, 2006**

[Day 46 Friday, 30 June, 2006](#)

Today is a day of outings. Not the kind of outings splashed on tabloid headlines and secretly read by concerned conservatives. No, these outings are the kind that mark Aaron's road toward independence, for us as significant as the national holiday coming next week.

The first outing comes with dawn: the gallbladder surgery drain tube. Drainage has slowed to a trickle, so Dr. Snickle says to Aaron "This may be a little uncomfortable" (which is another CODE, a special Doctor Code, for "You are going shriek in agony with excruciating pain"). A deft snip with the scissors, a quick tug by the doctor, and a sucking yelp from Aaron; the drain tube is out.

The TPN (food straight to the vein) having been discontinued, there is no further need for the PICC line (until the next round of poison). Dr. Lee repeats the special Doctor Code, works away at dissolving the adhesives around the line entry just above below the bicep on Aaron's left arm, then pulls out the foot long line that penetrated all the way to the superior vena cava just about the heart. Aaron's arm is pins and needles the whole way out. But the line is gone, and with it the last remnant of the tingling numbness. So Dr. Winston was right; it was the line after all. Nerves like the nourishment they get by staying close to blood vessels, so little unnatural goings-on inside vessels do not always escape notice by the masses of vigilant neurons.

The final outing of the day is the most momentous. One of the remarkable similarities between hotel rooms and hospital rooms is the location of the bathroom: it is almost always next to the room's door to the outside world. This is not a conspiracy to confuse hospitals and hotels: hotels, no matter how exclusive, could never with a straight face charge \$50.00 for disposable bedpans; for this reason alone (and there are many others) it is obvious that a conspiracy to confuse hotels with hospitals would never get far. The real reason is because hospital builders and hotel builders belong to the same union, and this union, unlike most unions, encourages humor. And like it or not, it must be admitted that just the thought of confused occupants stumbling into corridors at 3 a.m. looking for bathrooms is very funny.

Aaron's hospital room layout conforms to the standard. It's a good 12 steps from the bed to the bathroom. With dad pushing the IV stand behind, Aaron makes today's final and best outing. He does not confuse the hall door with the bathroom door, he makes the proper left turn through the bathroom door.

Such a fuss over Aaron sitting on the toilet has not been made in 28 years.

[2 Comments »](#)

**July 1, 2006**

[Day 47 Saturday, 1 July, 2006](#)

There are yet more outings today.

The bag-o-urine, always hanging from some strut or another near the foot of the bed, meticulously measured, observed, emptied and tested for 6 weeks, is emptied one last time and the Foley catheter, the bag's connection to the wellspring of Aaron's bladder, is taken out. Over the last 6 weeks, when Aaron was in the twilight between awake and not, he was often concerned that his urge would make for an embarrassing situation. We had to remind him more than once that he did not need excuse himself, wait till we left, or get up to go. Hopefully those subliminal reminders will be quickly forgotten.

The trachea tube, having been replaced twice by successively smaller diameter tubes, is now completely taken out. The tracheostomy hole, created by a small vertical slit pried open and held open by the tube, begins to close by itself. It will slowly close over the next few days. Would that all plumbing were so conveniently self-repairable.

While the blood drive is underway in Ojai (our deepest thanks and gratitude to all), Aaron consumes (via the last remaining IV line) another couple units of packed red cells. His hemoglobin, always low, has been dropping steadily for the last few days so he needs a pick-me-up.

As the blood is finishing, Gabi arrives from Ojai with a stack of DVD's and a marvelous Philips 7" DVD portable player from New Leads. Wow! Thanks! The player (which also receives and supplies composite video), together with a set of portable Logitech speakers, enables re-rigging the ancient hospital TV for better sound. (Another difference between hotels and hospitals is found in their respective TV's. Hospital TV's were excavated from the early Paleolithic, while hotel TV's tend to be of more recent historical origin. It's not enough that the hospital TV is ancient: it's sound is further degraded by it having been hijacked from the TV's bad speakers and re-routed to play through the nurse call button. When was the last time the sound quality of a nurse call button was reviewed by an audiophile magazine?)

We are grateful beyond measure that we are complaining of such things.

[3 Comments »](#)

**July 2, 2006**

[Day 48 Sunday, 2 July, 2006](#)

Sunday is a day of visitations: Aunts Janet & Gloria, Grandmas Boydston & Burke, Friends Dirk, Nathan, and Lisa. Together with the regular the regular crew, it's quite a crowd even though not everyone comes simultaneously. Aaron's room gets so crowded that Michelle (Aaron's nurse who's concerned reactions inspires us to tease her without mercy) feels compelled to scold us for being so many and thus possibly compromising Aaron's path to recovery.

The visitations do not explicitly focus on Aaron: he is, of course, the reason everyone comes to room 1041, but after each visitor ogles at Aaron's changes since last he was seen through the eyes of the visitor, the conversation becomes like that at any gathering of close family and friends where casual banter belies intertwining roots below the surface. Like the intertwining roots in a stand of old-growth redwoods, the roots of a community give its members identity and strength that a tree alone cannot attain. Like the trees in the stand, the growth of the individual is bound tightly to the growth of the community. The stand, its singular identity born of entwined plurality, reflects the Creator.

In spite of yesterday's new stitches, the incision from surgery starts to ooze again as diluted blood soaks fresh dressings. White cells, whose responsibility it is to help heal wounds, grow and multiply fast; white cells usurped by the enemy even more so. Fast growth is the criteria used by the poison to select which cells it prefers to kill. White cells that are hijacked by the enemy do not attend to their

responsibilities. Nor do white cells that are poisoned. So the white cells are compromised from both sides; by the enemy from within and by the poisons from without. Healing, then, is a slow process.

It was decided a couple days ago that, all things considered, a blood thinner to help dissolve and prevent clots would be beneficial. So Aaron pops pills of Coumadin (nice medical name for the common rat poison Warfarin. Take too much and you die.). As one might expect, rat-poison doesn't help heal an oozing wound.

The doctors indicate that the next round of poisons against the enemy will begin within 2 weeks.

## ***Out of the Hospital***

**July 3, 2006**

[Day 49 Monday, 3 July, 2006](#)

Independence Day comes a day early!

Aaron has progressed to the point where he does not need to occupy a hospital bed.

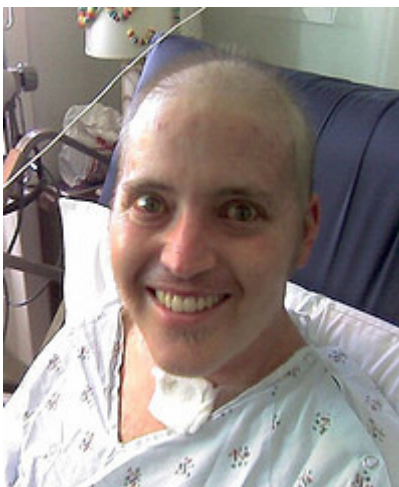
He is evicted from room 1041 to take up residence in room 214 of the Tiverton House across the street from the Medical Center. The Tiverton House is something of a hotel for patient families and a half-way house for a patients whose status is "out", but who are not quite ready to travel to distant homes. Room 214 has been crash pad for Natalie, pit stop for visitors, and home-away-from-home to Michaela, Christopher, and Grandma Metz for a good bit of the last 7 weeks.

The oozing from the surgery incision has stopped. Aaron feels inexplicably cold, but seems otherwise fine. He is starting to find his way around a keyboard again (yesterday he transferred his contact list from his old Treo (whose keyboard ceased working for Natalie while Aaron was hallucinating along through his parallel universe in the ICU) to its new replacement.

For 7 weeks, dramatic and sometimes life threatening change has been a daily, and often hourly, hallmark. The pace of change for now is slowing. For the next couple weeks, as Aaron gains strength for the coming battle, we will attempt to catch up on some of the exigencies of life that have been left undone. For the next couple weeks, updates to this journal are likely be more weekly than daily.

[9 Comments »](#)

[photos of aaron](#)



since i showed aaron a photo of himself for the first time a week and half ago, i've been taking pictures every visit. i set up a section of my flickr account for him so you can visually see his progress. [visit it by clicking here](#).

Chapter 1 • The Initial Trauma •  
May 16, 2006 – July 3, 2006

these are all taken from my phone, so i'll have to start bringing my nicer camera when i visit. it's still pretty interesting to see the differences between his photos taken [6/23](#), [6/29](#), and [7/2](#). his face is starting to thin out quite a bit, i assume because of bloating going down. anyways, enjoy!

- nathan stryker

[5 Comments »](#)



## Chapter 2 • “Regular” Chemotherapy • July 4, 2006 – January 27, 2007

### *Gaining Strength, Preparing for the Rest of Treatment*

**July 4, 2006**

[Day 50 - Day 56 Tuesday, 4 July - Sunday, 9 July, 2006](#)

Monday, July 10th, 2006

July 4th is celebrated with a wheelchair trip across the street to Best Buy, and later after a nap to recover a 20 minute ride with Dad to Fry's, which closed early, thereby requiring a second trip on Wednesday with Rose. There is in the material world little of interest to the geek-at-heart that cannot be found in these two establishments.

Fireworks at dusk are heard in the distance, but no pyrotechnic displays light the night sky outside the Tiverton.

Aaron continues to gain mobility, assisted by a round of physical therapy. His gait progresses from carefully tentative to oddly stiff to nearly normal by Sunday.

The staples and stitches come out on Thursday, and the last oozing from the incision finally ceases. The trachea hole is all but closed.

Aaron doesn't have much appetite; eating is more an obligation that he dutifully performs. He has lost nearly 40 pounds over the last 8 weeks. Few will be jealous of the means that led to this end. It is unlikely that we will see cytotoxins sold as diet aids, or a new diet bestseller touting chemotherapy (but then again, if rat poison can be used to eliminate blood clots, what isn't possible?)

Michaela wonders when her daddy's hair will grow back.

An appointment is set for next Wednesday with Dr. Paquette to review the progress thus far and to map out the strategy for the coming weeks.

[1 Comment »](#)

**July 11, 2006**

[For everyone who is still checking in...](#)

we would appreciate prayers as Aaron will have his BIG doctor's appointment tomorrow (Wednesday). At this appointment we should find out a lot more information about what will be done next in regards to Aaron's treatment. Please, pray for wisdom for the doctors, that all concerns will be addressed and for Aaron's continued healing. As we have done every step of the way, we continue to have faith in God. We wait patiently on Him knowing that all who put their hope in the Lord will not be disappointed. We thank you all from the bottom of our hearts for your prayers and support. We'll let you know what plans the doctors come up with!

[5 Comments »](#)

**July 12, 2006**

[Just a Quick Update](#)

Thanks for your continued prayers! We just wanted to update you on Aaron’s appointment this morning. After some discussion, it was decided that Aaron will return to the hospital on July 24th. He will then undergo his second round of chemo which should be less severe, according to the doctor. With the particular medication Aaron will be receiving, he will most likely not lose any more hair or feel really nauseous! I am thankful that the doctor said he would like Aaron’s chemo done in the hospital instead of at home. Having chemo done as an inpatient is a lot better because the duration will be shorter and more people will be around to monitor how Aaron is handling it. Right now, Aaron is working on getting stronger. He has periods where he feels crummy for a few hours at a time but there is nothing going on that concerns the doctors at this point. We are so thankful for God’s lovingkindness and care. We see His goodness everyday. He is truly an awesome and amazing God who works in marvelous ways—ways that we don’t always understand but that we know are the best ways.

Oh, give thanks to the Lord! Call upon His name; Make known His deeds among the peoples! Sing to Him...Talk of all His wondrous works! Glory in His holy name; Let the hearts of those rejoice who seek the Lord! Psalm 105:1-3

[2 Comments »](#)

## **July 15, 2006**

[Day 57 – Day 63 Monday, 10 July through Saturday, 15 July, 2006](#)

Dr. Ronald Paquette’s stature as a research oncologist, professor, and physician looms much larger than his slight, hurried presence in the stairways and hallways of the UCLA medical center, where he is usually little more than a smiling blur as he runs through his domain, making hurried contact with patients whose futures, together with his decisions, are profoundly entwined. His previous meetings with Aaron were quick, intermittent, and pretty much observational, as Aaron’s awareness was mostly absent and his immediate needs were being met by those whose goal was to restore that which the enemy destroyed. Dr. Paquette’s goal is to destroy the enemy.

At his first scheduled meeting with Aaron on Wednesday morning, he looks at Aaron and decides he needs more time to robustify before starting the next round of poisons, “consolidation”. For 4 days (unlike the previous 7), beginning on July 24th, poisons will again flood his body in relentless pursuit of the hidden enemy.

Aaron continues to improve unabated. He has gained a couple pounds and does not have quite the Auschwitz look. Exhaustion is continuous, nausea comes in intermittent waves. He has his first burger on Wednesday. The resulting nausea tempers enjoyment.

A fundraiser for Aaron (even good medical insurance leaves much undone) is scheduled for next Saturday at Lake Casitas in the beautiful and of late rather toasty Ojai Valley. It is sponsored in part by Aaron’s employer, New Leads, by the Ojai Valley Wesleyan Church where Aaron moonlights as youth pastor, and by the Ojai Valley Baptist church.

A troubled world would do well to peek in on Ojai, where community is more than a concept. A unity that flows from diversity among Ojai’s “competing” churches testifies that at least some things in this world are as they ought to be.

[6 Comments »](#)

## **July 21, 2006**

[Day 64 – Day 69 Sunday, 16 July through Friday, 21 July, 2006](#)

The weather this week in Ojai was served hot, with a generous side of swelter. The normal caveat to Ojai’s hot summer days “...it’s a dry heat” was absent from this week’s temperature menu. But triple digit days and Mississippi nights did not deter Aaron from visiting Ojai. This is summer camp week, a big week for the youth at OVWC. Last year, Aaron, Natalie, Michaela, and Christopher accompanied the gang to camp and returned hoarse, muddy, exhausted and looking forward to doing it again this year. But that was when the world was different, when plans were made, when the future maintained the illusion of predictability.

Aaron shared at Sunday morning service a bit of his hospital sojourn from his [highly altered] perspective. Beginning the third day after the ambulance trip to UCLA, the events lodged in Aaron’s memory bear no semblance to those in the records kept by the staff at UCLA and which might generally be confirmed by any even marginally sane witness. Aaron’s remembered events do not begin to intersect with reality until several days after leaving the ICU.

But while the events of Aaron’s alternate reality involve such bizarre thrills as being chopped in two, turned into a mosquito, and living in the cafeteria, recalled events do not constitute our most important memories. For the important ones, Aaron’s memory severed him well (perhaps the hallucinations actually did serve him well, if not accurately).

The copious and powerful narcotics could blunt his pain and alter his reality, but there was no alternate reality that was not painful, filled with suffering, and relentlessly miserable. Aaron remembers suffering; the memory of continuous misery is clear and doubtless.

Yet for all the affliction, there is also a memory of that which the enemy’s most miserable and twisted nightmare could not extinguish; there is the memory of hope. Never was there a moment when Aaron was not hopeful. That the light of hope should burst from the dark of misery and triumph over the darkness is the stuff of legend, fable, and Divine grace.

Monday morning, Tommy and lovely bride Vanessa, on staff at “competitor” church CLC and filling in for Aaron and Natalie as OVWC youth pastor (While the title is singular, it is only singular in the context of two becoming one.) pro tem pile into the caravan with the kids and head for camp. Aaron tried to make it to the staging area at OVWC to bid adieu, but his body wouldn’t cooperate.

His body being more cooperative later in the week, he did make it on Friday evening to greet them on their 4 hour late return, they having crawled from San Diego through Los Angeles in the Friday afternoon “Getaway”.

Posted in [Uncategorized](#) | Comments Off

**July 23, 2006**

[Day 70 – Day 71 Saturday, 22 July through Sunday, 23 July, 2006](#)

The breeze off Lake Casitas transformed Saturday’s swelter from unbearable to just plain hot and at times almost pleasant. Hundreds braved the heat for lemonade, tri-tip, lemonade, raffles, lemonade, music, lemonade, auction, lemonade, body art, lemonade, jewelry making, lemonade, sharing, lemonade, lemonade, lemonade, ice tea, water and sno-cones.

Events are curious affairs. They are ephemeral societies that form, evolve, engage, and evaporate. Whether the dedication of the Soldiers National Cemetery at Gettysburg in 1863, the March On Washington for Jobs and Freedom a hundred years later, Christopher’s butterfly party last year, or the fundraiser for Aaron on Saturday, the event is a fleeting moment birthed of protracted preparation.

The effortless ease with the temporary encampment of awnings, amplifiers, stage, firepits, galley, jolly jump, chairs, tables, booths, latrines, activities, and ice chests, grew on the grassy shores of Lake

Casitas testified to the considerable planning and preparation that grew Pastor Lyn’s germ of an idea into the event for Aaron that it became. Churches, businesses, organizations and individuals in Ojai (and beyond...word leaked out) contributed time, materials, and money to make this event one that will live in memory well beyond its fleeting moment in history.

The music and speaking on the stage had difficulty competing with the food and fellowship being consumed by company in the shade. There were two exceptions, which hushed all present: The announcement of raffle winners, and Aaron, as he without assistance took the stage and stood to give thanks and to testify.....”For me, to live is Christ...”

[4 Comments »](#)

## ***Second Round of Chemotherapy***

[The first round was in ICU]

**July 27, 2006**

[Requesting Prayer for our Friend, Eric](#)

We just spoke with Eric’s mom in the hall and she said that the doctors tell her Eric may not make it through the week. Some of you may remember that Eric spent a few weeks in ICU with Aaron. Eric has AML (like Aaron) but also has aplastic anemia. It seems to be the aplastic anemia that is the big problem for Eric. Anyways, we would greatly appreciate it if you would join us in praying for this family that we have been through so much with. It is awesome to see how Eric’s mom is trusting God. She has a faith in God that is absolutely amazing. Her most common phrase is “God has the last word on everything.”

Aaron will be finishing his last dose of chemo tomorrow morning. We hear that we will then be discharged to the Tiverton for about 3 days and then sent back to the hospital while Aaron is neutropenic (no white cells) for a couple of weeks. Please, also pray for protection for Aaron while he has no immune system. He had a pretty crummy day today—he felt nauseous and restless.

Many thanks to all of you who demonstrated so much love toward us through the fundraiser. Many of you put so much effort and work into making such a beautiful thing possible. It was such a blessing to be able to attend. We have been so blessed by God! Words fail to express how much gratitude we have in our hearts.

This trial that we are going through certainly has not been fun but it is so amazing to see how much good has resulted from it. It is certainly true that God can turn a curse into a blessing! Aaron and I know very well that we are serving God right now, just in a different way and in a different place.

Thank you for continuing to keep us in your prayers. We know that the joy, peace, hope and strength that we have is from God in answer to your prayers. God’s richest blessings to all of you!

[1 Comment »](#)

**July 28, 2006**

[Day 76 - Friday, 28 July 2006](#)

I finished up my second round of chemo today. I went back into the hospital on Monday and started the first dose chemo with quite a bit of misery. Thankfully my response to the subsequent doses (2 a day, eight total), was not nearly as bad, except for on Thursday, when I had a another very bad day. Each day consisted of injecting the poison into my body for 2-3 hours, at 6 am and 6pm. I find it very humorous how when they handle the bags of chemo they dress up in protective garb b/c they can not

July 4, 2006 – January 27, 2007

risk getting even one drop of the poison onto their clothing but they will put the ENTIRE bag of poison INTO my body! That is cancer treatment for you...

So now we are back at the Tiverton Hotel until Monday or Tuesday, depending on when my white blood cells go kaput. Then we will go back into the hospital for 2-3 weeks while my immune system slowly comes back. It will be a very sensitive time as simple sicknesses, such as the common flu, could be extremely dangerous to me when I have no immune system.

We still do not know about the option of stem cell transplants; we are waiting for insurance pre approval before even being able to look for matches. The doctors are still interested in pursuing it, though.

Thank you so much for you continued prayers and God bless you,

-Aaron

[6 Comments »](#)

## July 31, 2006

[Day 79 - Monday, 31 July 2006](#)

I got my blood tested today to check the white cell count. There are about 2,000 (normal is 5,000-10,000), so the doctor expects my immune system to be gone by Wednesday, which will then be the day I go back into the hospital.

I do not feel TOO bad from the effects of the chemo; just really tired, weak, and crummy.

That is about it for now; God bless you all!!!

-Aaron

[5 Comments »](#)

## August 3, 2006

[Day 82 - Thursday, 3 Aug 2006](#)

I came back into the hospital yesterday to be confined to my own little prison with a hepa filter larger than myself. I should be here from anywhere between 1.5 - 3 weeks, just waiting until my immune system comes back, and receiving blood and platelets in the meantime.

My insurance has finally pre approved the possible adult stem cell transplant, so Rose and Annalyse can get tested to see if they are a match with me.

Thank you all again, for your love and support!

In His Grace,

Aaron

[4 Comments »](#)

## August 6, 2006

[Day 85 - Sunday, 6 Aug 2006](#)

Getting my blood drawn. Ouch!

If you have never been woken up in the middle of the night by a needle probing for your vein, you really must try it sometime! It is a lot of fun. Or not... Every single night, anywhere from 2 am to 5 am,

the needle-and-tube bearing villain enters my room determined to fill up those tubes with my red stuff. The bummer is that the more I get poked the worse it gets b/c my veins are getting better and better at sensing the onslaught of the needle and promptly hiding. The needle then has to hunt and chase for the avoiding vein, and, man!, that really hurts! My arm is getting bruised from all the hide and seek, which makes the needle's job all the harder, which results in more bruising, which makes the needle's job harder, which... and on and on...

Still, though, overall things are going well. I have not yet gotten any of the expected side effects: fevers, mouth sores, messed up intestines, mental problems. It will be quite wonderful if I am able to avoid all those things. My neck has been hurting a lot though. Talk to you later.

I Love you all!

Aaron

[2 Comments »](#)

**August 7, 2006**

[Day 86 Monday, 7 August, 2006](#)

Sprinkled on the surface of nearly every cell in our bodies are a few different kinds of complicated protein molecules with the fancy name of “Human Leukocyte Antigens” (HLA's). These proteins aren't exactly sprinkled willy-nilly. In fact, in each person, they are arranged exactly just so, and exactly the same on every cell in that person. Our bodies' defenders, The Leukocytes, use these arrangements as a sort of Braille code to identify friend or foe. The Leukocytes roam the body, blindly bumping into other cells. But this bumping isn't accidental. Like skilled Braille readers, the Leukocytes feel for the matching codes; when they encounter a bacterium or a foreigner's cell, they sense that the should-be-just-so proteins are not just so. Illegal alien! No questions are asked, no deportation hearing is scheduled. The stranger cell is killed.

Today, Rosemarie and Annalyse walked into the lab at 200 Medical Plaza, across Westwood Avenue from the Jules Stein Eye Institute and walked out an hour later less 6 tiny vials of fresh warm blood...about 1/3 of a cup all told. There is about the same odds as when you pull the lever on a Las Vegas slot machine (a tad under 50-50) that the Braille code on the blood cells in 3 of the vials will be close enough to the code on Aaron's cells that that the sister's Leukocytes could be fooled by Aaron's cells. The blood will be examined by the lab's magic decoder rings which will crack the Braille code and compare it to that of Aaron's cells. If they match close enough, either Rose or Annalyse will qualify to be a stem cell donor.

Stem cells are the cells that become all other cells. Stem cells don't do much if left alone except stay alive and reproduce. But stem cells, for all their apparent languid, life-o-Riley living, have an amazing talent. If a stem cell is finessed in just the right way, it can turn itself into just about any kind of cell found in a living creature. Inject a stem cell into a heart, it can become heart muscle; put it in bone marrow, it can become blood. Incarnate transubstantiation, if you will. A melding of genetic disposition and environmental influence. (It used to be thought that only offspring of the few-dozen stem cells found in a pinhead-sized, 4-day-old embryo could accomplish such magical sleight-of-cell. Over the last few years it has become increasingly clear that stem cells by the millions found in folks thousands of days old can perform many of these same transmutational tricks.)

While the enemy in Aaron's body that has subverted his Leukocytes is at this point in deep hiding and bearing the brunt of the further attack from consolidation poisons, it will likely be only a matter of time after the chemical warfare ceases that the enemy will emerge from hiding to continue its horrific brand of terrorism. If this enemy is to be defeated, not only Aaron's Leukocytes must be destroyed, but the

deep hiding places where they are spawned must also be destroyed. The cells that make the cells must be destroyed.

So here’s the plan: Aaron will receive a fatal dose of poison, (and possibly also radiation), so intense that not only his Leukocytes, but his complete immune system, all the bone marrow and all the stem cells, will be irreparably destroyed. Then, just in the nick of time, stem cells from a donor will be injected into his blood. These stem cells, not having been subverted by the enemy, will settle into the bones, begin to reproduce, and begin make new untainted stem cells, new marrow and new blood, completely free of the enemy. In a co-mingling ineffably sublime, the donor’s stem cells will become Aaron.

It will be a week or so before we find out if Rose or Annalyse will be a match. If they are not, the search will widen. Siblings have a much higher chance of matching than anyone else. The odds plummet from not-too-bad Las Vegas odds to astronomically-bad winning-the-lotto odds. But there is a growing international database, now in the millions, of potential stem cell donors that have signed up for this Pick-Six lotto, so overall, the odds are not too bad. Unlike state run lotto’s, the more that play this game, the better odds.

While it is pretty unlikely that any family or friend other than Rose or Annalyse will match, you never know. And while most donor registrants will never actually donate cells, you just never know. You also never know whether, no matter how well matched, the donor’s cells will recognize the ruse, see Aaron as an alien, and attack. You just never know if a second donor or even a third donor might be needed for the hat trick.

But what you do know is that if you don’t play, you won’t win. And you know that if you do win, you win big; You win the gift of life for another.

The game in the U.S. is managed by the National Marrow Donor Program. More information can be found at:

<http://www.marrow.org/>

(It’s called “Marrow”, because just a few years ago, to get the stem cells, it was necessary to dig marrow out of bones. Nowadays, donating stem cells is usually a lot easier. It’s like giving blood, except you imbibe a colony stimulating factor like filgrastim or such for a few days before that makes you feel like you have a mild flu, and you get to lie down a couple hours instead of a few minutes. Instead of your blood being taken away and bagged up, it flows though a clever machine that plucks out the stem cells and courteously returns your blood to you.)

[3 Comments »](#)

**August 8, 2006**

[Day 87 - Tuesday, 8 Aug 2006](#)

I got a fever yesterday. As soon as the thermometer registers 38 degrees celsius or higher, it triggers antibiotics, cold sacs, blood tests, and tylenol. The fever subsided some but I woke up during the night to vomit. So far I am feeling better today; praise God!



I thought you all would enjoy a little hospital food with me. I call this my breakfast ball. Who can guess what this is?

-Aaron

[5 Comments »](#)

## August 10, 2006

[Day 89 Thursday, 10 August, 2006](#)

As Aaron, [was] in acute respiratory distress and struggling for every breath, [and] was being wheeled out of room 1040 and down to the basement ICU nearly 3 months ago, he yelled back the last words we were to hear from him for a month: “Get me a bigger room!”

Room 1001, at the east end of the 10th floor, is definitely a bigger room; by hospital standards, posh (by hotel standards, Econolodge, but whose comparing?). When Aaron began induction 2 weeks ago and scored room 1001, his request was granted...for a short while. Then, Nancy Riordan, wife of Los Angeles ex-mayor Richard Riordan whose successful business career before his stint as mayor netted him a reputed worth of some \$100M, checked in. Aaron got the boot, and Nancy got the room. UCLA medical center, quite understandably, is just a tad less democratic than cancer.

Now Aaron has come full circle, back to the more plebian quarters where he started...back to room 1040.

Twice in the last week, UCLA has run short on platelets. Twice, Aaron managed; first by winning the “who needs them worst” competition, and second by the good graces of our Ojai neighbor Linda, for who’s timely visit to the platelet donation center we are grateful indeed.

Aaron’s blood counts continue low. Regular packed cell and platelet transfusions keep things under control. Intermittent nausea, vomiting, fever, exhaustion, and pain are reminders that Room 1040 is really not a small room in an overpriced vacation resort.

[1 Comment »](#)

## August 11, 2006

[Friday’s Update](#)

Aaron asked me (Natalie) to let everyone know how he is doing. He basically feels pretty miserable. He has been having fevers since Monday and has a 102.4 temperature right now. He feels pretty nauseous and is hoping to get some medicine for that tonight. Today, he developed pain behind his left eye. The doctors say that he has episcleritis (inflammation in the white part of his eye) but don’t see any reason that he should be having pain. He will probably be visited by an ophthalmologist tomorrow. At .4, his white cell count continues to remain in the neutropenic range. He feels too bad to



watch t.v. or post on the blog or do much of anything. Hopefully, Aaron will get through this part soon and we can go home for awhile!

We are so glad that we can keep in touch with all of you through this website. Thank you for checking in and praying for Aaron. God is teaching us to rely on Him. We know that He is in control and He is giving us strength as we wait on Him. We love you all so much and are blessed to have you supporting us!

Blessed be the Lord, who daily bears our burden,  
The God who is our salvation. Selah.  
God is to us a God of deliverances;  
And to GOD the Lord belong escapes from death. Psalm 68:19-20

[3 Comments »](#)

## **August 17, 2006**

[Day 96, Thursday, 17 Aug 2006](#)

A REAL IMMUNE SYSTEM!!

We were discharged very late last night, and headed over to the Tiverton House. I am feeling quite a bit better after getting over the fevers of the last few days.

I got my blood test results from this morning and I have a real immune system today (albeit the lowest end of \*normal\*)!! For a while, my body was not retaining platelets, even the ones they were giving me regularly, but they seem good now.

Neither Rose nor Annalyse are stem cell matches with me so I am not sure what the next course of action will be. It may simply be multiple (2-3 more) rounds of consolidation chemo (exactly what I just finished with) or they may search for a match elsewhere or they may want to use my own stem cells. I have a doctor's appointment in a week and should have some clarification then (presumably).

BTW, the breakfast ball is a very \*tasty\* corn beef hash mound.

God bless you all!

-Aaron

[8 Comments »](#)

## **August 23, 2006**

[A Very Nice Reprieve! Day 98, Wednesday, 23 Aug 2006](#)

We met with Dr. Paquette today and we got the scoop! And it includes a very nice reprieve!

Here is the plan: 1) I will have 3 weeks off to recoup (doing that at this very moment!); then a week of chemotherapy in the hospital; then a few days out of the hospital until my immune systems disappears; then two weeks of neutropenia (no immune system), in the hospital. 2) Then I will again have 3 weeks off to recoup; then a week of chemotherapy in the hospital; then a few days out of the hospital until my immune systems disappears; then two weeks of neutropenia (no immune system), in the hospital. 3) Then I will again have 3 weeks off to recoup; then a week of chemotherapy in the hospital; then a few days out of the hospital until my immune systems disappears; then two weeks of neutropenia (no immune system), in the hospital.

And then I will be done!!!! Okay, so it seems a bit strange to me to be so excited about a road ahead that is still pretty long... but I am. I guess it is really nice to have a clearly plotted course and “regular”

chemotherapy is nothing compared to what I have already gone through. Of course, complications are likely, so the road may very well change, but hopefully not!

So for the next couple weeks I will be in Ojai. We are trying to move out of our apartment, because of mold, and find a new one, because the doctors do not want me living in a moldy environment. Thankfully we have had a lot of help moving out, since I, myself, am not good for much! Please pray that we find a nice clean (no mold!) place to move into. In fact, we have a particular place in mind (Montgomery Oaks apartments), and are hoping that a unit becomes available soon.

Regarding a stem cell transplant (bone marrow transplant), I will only need one IF I relapse, which, God willing, WILL NEVER HAPPEN! Thank you, all, for so many offers to be tested to see if you match with me. As Gail mentioned, though, it is great for everyone to be tested. If I understand it correctly, the way it works is that once you are tested you are added to a database. Then when someone needs a stem cell transplant, the database is searched and you may save someone's life!

Things should be pretty quiet for the next few weeks; thanks to all of you that keep in touch by posting (and those of you that just read too!!!). I appreciate and enjoy reading what all of you have to say.

God bless you all richly!

-Aaron

P.S. You may notice something funny about the day count above. I think I may have messed up the count at some point when my faculties were not all there. I just did a “fresh” count and today is indeed day 98, just over 3 months... wow.

[7 Comments »](#)

### ***Third Round of Chemo***

**September 18, 2006**

[Here we go again!](#)

Today I am starting my third round of chemotherapy. I am getting the poison pumped into me as I write. Fun, fun fun!

These last few weeks were such a wonderful break. Got to go to church, to youth group, to my office meetings and got some little projects to work on. Got to drink some coffees! Best of all, of course, I got to spend lots of time with Natalie, Michaela and Christopher. Overall, I have been feeling pretty ok, which, relatively speaking, is really wonderful!

This last week, though, was a bit of a downer with the ominous threat of chemo on the horizon. Similar to that feeling you get at the end of a vacation or Sunday afternoon, when you know you have to go back to work, so it is kind of hard to enjoy yourself. But it was still very nice.

We are completely moved out of our old apartment and living with Natalie's parents or in the hospital or at the Tiverton (hotel across from the hospital). We have a specific apartment we want to move into: Montgomery Oaks apartments. It is just a couple blocks away from our old place and we are on the waiting list. So we are, well... WAITING.

Marsha Penrod, It was great seeing you two too! And, yes, I enjoyed my coffee.

Rebecca Kerr, Yes, direction is so nice. And if God wants us in the Montgomery oaks it will be easy...  
:)

Instryker, Yeah, you came to ojai!

cynthia engle, it was so great to see you the other day, even though it was just for a minute.

Rachael, I am so glad that our experience has served as an inspiration to others and thank you for the opportunity to pray for your mom.

Rick and Kris, thank you for your prayers. I often think how crazy/weird/wonderful it is that just several weeks ago I was barely able to open my eyes and now I am up and about and able to most things (just at a lower level).

ingrid, I can't wait to see those pictures!

God bless you all so much and thank you for everything!

-Aaron

[3 Comments »](#)

## September 21, 2006

[Fever \(by Natalie\)](#)

The latest news is that Aaron got a fever this morning. There is not really a reason why he would be having a fever already. The doctor guesses that it could be a bacterial infection. Aaron had a chest X-ray and blood cultures and we are waiting for those results. In the meantime, they just started him on antibiotics. The biggest bummer is that this means we won't get to leave the hospital for a few days after the chemo finishes tomorrow. Usually, you have to go “home” for 4 or 5 days after receiving the chemo while you are waiting for your immune system to disappear. We were all looking forward to those few days together before spending another 2 to 3 weeks in the hospital. So, please pray for Aaron. He feels extremely crummy and couldn't even get out of bed to wave out the window at the kids today. Also, we would be very grateful if you could please help spread the word that Aaron is in need of extra special prayer.

I'm homeschooling Michaela and her Bible lesson today (to fit in with our farm theme!) was that we are “under His wings.” We read Psalm 91 and talked about how God protects us, just like a mother hen gathers her chicks under her wings. Like the baby chicks, we are protected when we run to Him and we need not fear for our safety. It is an awesome word picture, one that I am glad the Lord brought to mind today!

Psalm 91:4-7, 9, 14-16

He will cover you with His wings; you will be safe in His care; His faithfulness will protect and defend you. You won't need to worry about dangers at night or arrows during the day. And you won't fear diseases that strike in the dark or sudden disaster at noon. You will not be harmed, though thousands fall all around you...The Lord Most High is your fortress. Run to Him for safety...The Lord says, “If you love Me and truly know who I AM, I will rescue you and keep you safe. When you are in trouble, call out to Me. I will answer and be there to protect and honor you. You will live a long life and see My saving power.”

[4 Comments »](#)

## September 22, 2006

[I'm so proud of Aaron!](#)

I tell Aaron everyday, a hundred times a day, that I am proud of him. He is amazing. I am so blessed to be his wife. He is in an extreme amount of pain and discomfort and yet he never complains and rarely gets irritated with anyone. He has and is suffering through something that is completely

miserable while retaining a good attitude. Yesterday was so hard for him. He slept all day and woke up only to vomit. Then, one of the nurses accidentally ran the potassium through the IV without the fluid (to dilute it) which had him writhing around in pain because potassium, I hear, burns like crazy. He only spoke about 10 words all day. But, he toughed out yesterday. He is a trooper. I praise God for giving Aaron strength and patience. And a double praise God because not only is Aaron feeling a little better today but he has not had a fever today. So far, test results show that he doesn't have an infection. A couple other test results are still pending. He hasn't eaten anything at all since Wednesday and he is too miserable to do anything except sleep but I have heard a few jokes today. This morning was his last dose of chemo so now he is just working on recovering from its effects. Anyway, I just wanted to give a quick update and let you all know how great a job Aaron is doing. Thank you all for continuing to check in and for posting comments. It is an encouragement to hear from you all and know that you are still praying for us.

“Come and see what our God has done, what awesome miracles He does for His people!” Psalm 66:5

[4 Comments »](#)

## September 26, 2006

[My Official Recommendation](#)

Well, I have thought a lot about it and I have decided that I officially recommend you NOT get acute myelogenous leukemia. Or any other cancer, for that matter! :)

So far, this round of chemo has been quite a bit more miserable than the last round. Kind of interesting how different it is, though it is not exactly a study I wish to conduct. :) Then to top it off, the hospital TV has very few channels and a bunch of them are not working due to technical problems! But on the bright side, I am often too miserable to even watch TV, so it does not matter. Oh wait, that is not really a bright side... Oh well... I tried. Wait, let me try again and this time I will succeed: On the bright side, God's grace is so wonderful! His mercies are new every morning. And that is a very bright side!

-Marsha Penrod, thanks for the mention of Tracey Chapman's hepa filter. I will let you know if we need to contact them. Thanks for the kind words and I checked out your website. Very nice! :)

-Rebecca Kerr, very unfortunately it is a bad time for any visiting because my missing immune system. Very, very unfortunate, b/c we would love so much to see you guys!

-Jack Hager, thanks.

-Instryker, not much occurs to them, period.

-Laura Burton, thanks.

-Susan Burke, are you saying you are offering me your sore throat and insomnia? Thanks, A. Susan! :)

-Barbara Resnikoff, thanks and I hope to get back and give better support!

God bless you all. In His Grace, Aaron

[3 Comments »](#)

## September 27, 2006

[One of the best sentences I have ever heard...](#)

...was when the doctor said, “you should only have one more round of chemo after this.”!!!!

PRAISE GOD!!!! Now, I am holding off getting too excited b/c previously it was very clear to us that I would have two more rounds after this. So maybe it was a miscommunication but I am waiting until further conversations with Dr. Paquette before totally believing it.

Wow, if I only have one more round, that will be soooooo NICE!

-Instryker, you know, I have always thought, “better your thoughts and prayers than your gemy selves.” :)

-Shyle, that is so funny, I was just singing that song to my kids for the FIRST TIME the day before coming back into the hospital!

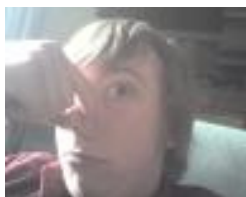
-Jack Hager, and I am healing. Praise His name!

[4 Comments »](#)

**September 30, 2006**

[Nathan](#)

Nathan started this blog for us, back when I was diagnosed, and then he taught me how to post an image, so I posted his picture. This is a picture from one of his recent photo shoots (I think). :)



[2 Comments »](#)

**October 1, 2006**

[The Excitement of Hospital Life](#)

Just to give you an idea of how exciting hospital life gets...

I just recieved one of my delicious meals and the plate was covered with a brand new clear and shiny lid! It was my thrill for the day.



Also, I have discovered that I can watch Law & Order pretty much anytime of the day. This is made possible by there being multiple versions of the show and multiple stations carry them. Sometimes it is even on different channels at the same time! That is really nice because then I can pick which episode I want to watch.

So that is my exciting life in the hospital! (I guess I should mention fevers and vomiting and stuff, cause they do mix things up a little.)

nstryker, \*smack\* (our hands hitting)

Scott Travis, I am glad someone is taking my advice. :)

Rebecca Kerr, I hope you and your family feel better!

[5 Comments »](#)

**October 7, 2006**

[Discharged \(by Natalie\)](#)

We were kicked out of our hospital room last night because Aaron’s neutrophils increased rapidly due to the Neupogin shots he has been receiving. This means that Aaron has an immune system now and is not covered to stay in the hospital any longer. We are at the Tiverton until Wednesday, at least. During the other two rounds of chemo, Aaron didn’t receive neupogin shots so this is his first time getting them. The shots are supposed to make your neutrophils/white blood cells come back faster so that you get your immune system back faster. The shots have given Aaron some unpleasant side effects: extra nauseous, huge bruises where the neupogin is injected and petechiae (broken capillaries that look like a rash—which by the way was our first sign that anything was wrong back in May). He feels awful and had to ask me again to post because he is not up to it. So, even though it is good that Aaron’s white cells are coming back, it is a little unsettling leaving the hospital when he is not physically strong enough and ready to do so. He also switched to a different pain medication (because he is now outpatient) and that did not agree with him at all. He started getting shortness of breath and a rapid heartbeat. Now, that we figured that out and got his medication switched, we are praying he will start feeling better. He has two more days worth of neupogin shots and an appointment with Dr. Paquette on Wednesday. After that, we hope to return to Ojai for a few weeks before the next (and hopefully final!) round of chemo.

Your calls and posted comments continue to be much appreciated. We also would appreciate your prayers for Aaron to feel better. He is such a tough guy—he has to put up with so much. I think it is starting to make him a little weary so please pray for strength and encouragement. We love you all so much and cannot even begin to express how thankful we are for your support.

I have been thinking a lot these last few weeks about just how big a miracle God did for us. I was determined from the very beginning to take Aaron to Jesus and trust Him with Aaron’s life. And, He did not disappoint me! When Aaron was in ICU for those 4 weeks, sedated, I got a sense of what it would be like for him to be dead. There were no signs of life from him except the numbers on the screens. But, praise be to God! In a way, He raised Aaron from the dead for me. This is huge—it is our very own healing miracle just like we see in the gospels. And as for Aaron’s continued recovery, I am excited and encouraged as I think about the fact that God does not do half-miracles. He parted the Red Sea the whole way across. When He healed those who were lame, they didn’t just slowly start to regain some of the use of their leg and hobble across the room, they started leaping! My God is great—stand in awe and wonder at what He has done for us!

He who began a good work in you will be faithful to complete it! Philippians 1:6

[4 Comments »](#)

**October 12, 2006**

[A Little Catching Up](#)

First of all, I am feeling a whole lot better. Praise God! This last discharge was a very tough one because of pain medications and neupogin. I was on a pretty high level of pain meds in the hospital and starting having really bad withdrawals after going thru most of Friday with nothing. As Natalie mentioned, I then put on a pain dispensing patch that did not sit well with me. So I took the patch off after half a day, and put myself on a much lower dose of pain meds and then just suffered thru the

withdrawals and the neupogin-crummyness for a few days. Not fun! Now I should be sailing on smoother waters as I am done with the neupogin and continue to gradually decrease my pain meds. Secondly, we arrived back in Ojai yesterday afternoon! It is so nice to be home. Well, not exactly home because we are out of our old apartment and staying with Natalie’s parents until we find a new place. But great and wonderful thanks to Alden and Sue for taking us in for a few months! We are still hoping for a place at the Montgomery Oaks apartments; we will see... So, it nice to be back in Ojai for a few weeks!

Okay, and now for a little “Fun with Hair [falling out].” The doctor said I should not loose my hair this time, but... he was wrong! When it got nice and loose, a few days ago, I had a little fun giving myself an unmohawk. Fun!



As it got looser, it started to really bug me with it just sitting there slowly falling out all over the place, so we helped it along a bit! This is Natalie peeling hospital tape off my head, taking gads of hair with it. Fun!



Thirdly, YES INDEED, ONLY ONE ROUND OF CHEMO TO GO! WOOHOO! And then a lifetime of remission...

Nolan, I think the plate cover design was originally a bed pan. But that whole in the middle was a poor bed pan feature! :) So they realized the design was better suited for a plate cover.

Walt and Melanie, sorry we missed you! Maybe come and stay at my parents for couple nights some time soon. Hmmm???

Pastor Scott, God has and is indeed using this for His glory! It cheers my heart to no end to hear that our adventure has blessed so many people in a myriad of ways. I have often thought, “Wow, God is using me to bless people, and all I have to do is lay here and suffer.” It really makes it worth it.

Rebecca Kerr, Yeah, I know how you feel with a lack of trust and expectation and continued faithlessness in the midst of God’s continued and perfect faithfulness. But all the more reason to rejoice (and I will say it again, REJOICE!) in His marvelous grace!!! Oh, He is so wonderful to us...

Pastor Lyn, we do rest assure because of your (and others) love and prayers!

Marsha Penrod, yeah, I get a “kick” out of the whole chemo thing too. It is NOT like alcohol where it is poisonous if you have TOO MUCH. The chemo drugs are extremely poisonous right away! As soon as they enter the body, they start killing you. The trick is that the cancerous cells are always the weakest cells, so they get cooked first! It is just a very controlled destruction. And it is crazy!

Laura Burton, I am so glad that our adventure has refreshed your faith. Praise God!

[8 Comments »](#)

## ***Fourth Round of Chemo***

**November 13, 2006**

[Back Again, One More Time](#)

Well, here we are again, ready to begin the roller coaster ride that is chemotherapy. A roller coaster that only has low points, that is. :)

This last week has been a lot like going into work on a Friday. Yeah, it's not the weekend yet, but just one more day of work. We are not done yet, but just one more round! They should be bringing me my first dose of chemo any minute now, which is always the worst dose. So here I go again, one more round...

[8 Comments »](#)

**October 16, 2006**

[Done With Chemo \(by Natalie\)](#)

Aaron is finished with chemo! He was supposed to receive 2 doses a day for 4 days—a total of 8 doses. However, the doctors decided not to give him the last 2 doses because his liver enzyme level is too elevated and they were thinking that it may be due to receiving the chemo. So, they discontinued the chemo as a better-safe-than-sorry type of thing. His main doctor stopped by and said he does not believe that the increase is due to the chemo. He wasn't concerned and was laughing about Aaron sneaking out of the last 2 doses. I did some looking around on the Internet tonight and discovered that one of the steroids Aaron is receiving causes elevated liver enzyme levels. We mentioned it and the doctors decided to discontinue that as well. If Aaron's liver enzyme level comes down and he does not get a fever, we might get to go to the Tiverton for a few days before he is neutropenic. Tonight, he is getting a little feverish so we will see what happens.

Before we left for this hospital stay, my main prayer was that this round would not be as harsh on Aaron as the last round was. So far, that has proven to be true and I am grateful to God for that. We appreciate everyone continuing to stand with us in prayer. Much love to you all!

I will praise you, Lord, with all my heart;  
I will tell of all the marvelous things you have done.  
I will be filled with joy because of you.  
I will sing praises to your name, O Most High. Psalm 9:1,2

[4 Comments »](#)

**November 20, 2006**

[A Short Little Break from the Hospital Confines](#)

On Friday, they let us out for a few days. I had started to get a little feverish but thankfully it was minimal and immediately subsided. I am not feeling too bad yet, just waiting...

It looks like I will be admitted back into the hospital on Wednesday, for a hospital Thanksgiving! We picked up some cute Thanksgiving paper ware so that we can celebrate in style. We even got a welcome mat, at the 99 cent store, to create the Thanksgiving ambiance!



BTW, I have discovered more and more, that loosing my immune system from the chemo is somewhat specific to AML treatment. It makes sense, since AML is a cancer of the bone marrow. Only one more time, though!

Felicia Torres, don't worry about it!

nstryker, I started designing the coaster, but once I got the track engineered in my super duper computer roller coaster simulator, it actually did not seem too thrilling.

Ryan Vick, I too am glad you did not get sick and die! I am going to give you a hug next time I see you for doing that. :)

And to everyone else, thank you so much for your comments, we love them so much!

[1 Comment »](#)

**November 22, 2006**

[So Thankful!](#)

Happy Thanksgiving! We have a lot to give God thanks and praise for every Thanksgiving (actually everyday!) but this year we have extra blessings to celebrate. God has done an amazing miracle in choosing to heal Aaron that we have seen with our own eyes. God is good all the time. Here is a small list of things that we are thankful for this year!

AARON:

staying with my family - food - my wife and kids - somebody always staying with me in the hospital - having company - God touching so many hearts through my sickness - playing video games with friends - my job at Newleads - Tommy and Vanessa running our youth group ministry while we have been gone - that my kids are so much fun - the youth in our youth group - Wet Ones - God's truth - friends - all the incredible love and support we've received - how sweet Michaela is when I get out of the hospital - my Treo - being able to stay at the Tiverton so that my family is close - that there are so many things that we are thankful for that we can just randomly list things and not run out of things to list

NATALIE:

that what God says in the Bible is true - a host of amazing family and friends - an intact family - beautiful children and a wonderful husband - learning about faith and other lessons - Dr. Paquette, doctors and nurses, who have had wisdom and skill dispensed to them by God - all the wonderful people we have met at UCLA who tenderly care for the sick everyday - the power of prayer - coffee - being able to homeschool - an omnipotent God who is in control of everything, there is nothing too difficult for Him! - a God who smites - an omniscient God: He knows. We don't have to figure anything out—just trust Him! - an omnipresent God: being able to look back at the last 7 months and see God's hand of protection all along - Be anxious for nothing...He is near! - Jesus Christ, our Redeemer - not having to worry or fear anything

MICHAELA:

Jesus - doggies - Mommy and Daddy and Brother - animals - snakes (the good ones) - trees - policemen and firemen - flowers - aunts and uncles - sun - toys - electricity - Little Bear (her stuffed bear) - outside - horses and ladybugs - UCLA - the ground - rainbows - libraries - doctors

CHRISTOPHER:

sleeping - Mommy - water - TV - Mommy - playing games with Johanna and Sister - grandmas and grandpas - trashcans - cereal - Sister - Christmas - mirrors - Daddy - goo

Thank God! He deserves your thanks! His love never quits! Psalm 136:1

[3 Comments »](#)

## ***Rigors***

**November 25, 2006**

[What a night! \(by Natalie\)](#)

Wow! We haven't had a night that was as stressful as last night in a very long time. First of all, let me say that I am so grateful that we had a nice Thanksgiving. It was interesting and even fun. Aaron would tell everyone who came into his room “Happy Thanksgiving!” He even pushed the nurse call button to just say “Happy Thanksgiving!” That made everyone laugh a lot all day long. Aaron felt pretty well and we got to celebrate God's blessings with my family and Aaron's family.

Anyway, everyone went home to Ojai, so on Friday night, it was just Aaron and I. He started talking gibberish at one point and I thought he was drowsy from all the benedryl he got to prevent an allergic reaction to the blood he was getting. I told the nurse though and she took his temperature and it was 103.1 degrees. The nurse was adamant that his temperature come down. So, I got to use my fever-reducing skills that I picked up in the ICU. It basically involves laying washcloths that have been dipped in ice water all over his body and replacing them every 5 minutes after they warm up. It was pretty miserable for Aaron but he didn't even complain! Praise God, it worked and his temperature was 99.3 after 45 minutes.

He felt really well for about an hour and a half but then all of the sudden around 2 a.m. he started shaking/shivering violently and uncontrollably. He was shaking so hard that he was in a lot of pain. Within a few minutes, there were 2 doctors and 3 nurses in the room. He was shaking so hard we couldn't take his temperature because it would just fly out of his mouth but we did get it under his arm and he was about 101 degrees. As soon as they started taking his vitals, they saw that his heartrate was super fast-like 160- and his oxygen concentration (which is supposed to be between 95% and 100%) was between 75% and 80%. Basically, he wasn't able to breathe. So, they put him on an oxygen mask. The nurses and doctors that were there frankly were pretty panicky, they didn't know what was going on. But God sent in a Resident who knew what was going on. He said it was called rigors and that it was due to the fever Aaron had. He got Aaron some demerol and within a few minutes the shaking subsided. The whole thing lasted for about 15 minutes. He didn't stop shaking violently at all during that time. Thankfully, Aaron did not need the oxygen mask after the rigor stopped. Aaron said it was so violent of shaking that he was thinking this must be what a seizure feels like. Just before he got the demerol, he was about to ask for something to put in his mouth because he was starting to bite down on his cheeks. It was pretty scary to watch but I knew Jesus was in control which made all the difference in the world in being able to handle it.

Because of all this, the doctors wanted to get Aaron on a monitor so that his heartrate, blood pressure and oxygen concentration were being watched continually. He hasn't had to be on a monitor in over 4 months but this will be good in case it starts to happen again. Since they don't have the ability to remotely monitor a patient on the 8th floor where we were, we had to move up to the 10th floor (home sweet home!). Actually, we are back in room 1040 where we started out! We were all settled in our “new” room about 5 a.m.

The doctor came in this morning and said that Aaron likely has a bacteria in his blood and no immune system to fight it because he is neutropenic. That is probably where the fever came from that caused the rigor. He is receiving the best antibiotics that you can get and that is helping him fight the bacteria. The doctor said the first fever is always the worst and they do not expect him to have another rigor. He is still being monitored though. Right now, Aaron is great, Praise God! Maybe a little fever but well enough to sit up and play a game on his computer. Please, pray for no more high fevers! And, Praise God also for antibiotics! After trusting Jesus through the difficult events of last night, I feel like King David did when he said:

How the king rejoices in your strength, O Lord!  
He shouts with joy because you give him victory.

For you have given him his heart's desire;  
you have withheld nothing he requested.

You have endowed him with eternal blessings  
and given him the joy of your presence.

For the king trusts in the Lord.  
The unfailing love of the Most High will keep him from stumbling.

Psalms 21:1,2,6,7

[5 Comments »](#)

## December 2, 2006

### [Almost Out of Here](#)

Everyday brings us closer to the (sort-of) finish line which looks to be this Monday, Tuesday, or Wednesday at the absolute latest! The thought of getting back to regular life is just wonderful. Being able to really be there with and for my family, getting back my great job, and returning to church and Youth Group... there is so much I miss about it all (mostly all the relationships God has blessed me with!) it almost makes me cry. It was funny; I started to post the other day but then I received my pre-medications for platelets which includes 50mg of benedryl through my IV. Now if you thought benedryl knocked you out when taken orally (or if it does nothing to you, when taken orally), try it through an IV. Woa! Talk about getting slammed onto your bottom. It only takes a few minutes for me to begin slurring my speech like I am intoxicated, and then a few minutes later, nothing but zzz's. So that post was lost...

My status right now is “on the upswing!” My white blood cells are beginning to come back which also mean I am starting to feel better. After the previous round of chemo, I received a drug called neupogen, which helped the immune system return faster but also seemed to help me feel crummier. Also, it brings the immune system back unnaturally, so there is a risk of over developing white blood cells (this happened last time) and a small risk of regression after the drug is stopped. This time I refused the neupogen and, so far, I am very happy about the decision. One more, very important, thing to mention is that we will be having a party to celebrate finishing! No date or place yet, but EVERYONE is invited, and it will probably happen in January. Please post any ideas and suggestions! God bless you all so much.

EDIT: (I had meant to include the following comment when I originally posted, but forgot. So here it is.) Regarding the hospital food, I could be getting out of here none too soon! I am getting to the point where I, literally, can not eat the food sometimes. They put the “food” in front of me and, though I am hungry, I am just unable to eat any of it. Yuck! Real food, I am soon coming for you...

[5 Comments »](#)

## ***The Last Discharge***

**December 11, 2006**

[Out of There!](#)

On Tuesday, we got discharged from the hospital for the last time!!!

On our way out, we had a very special experience. We ditched “escort,” who usually lead us out, and decided to stop by the ICU, where I spent so much time earlier this year. We peaked thru the doors but did not notice any nurses that were well known to us. But before we could leave the nurse in charge of the ICU came to the doors, recognized us, and said to, “Come in!” Immediately, a commotion was started as nurses remembered us, even though none were the main nurses that took care of me the most. It was so amazing how touched they all were to see me “doing so well.” Just the fact that I was alive was a pretty big deal to them! There were even some tears from some of them, and a couple of nurses chased after us when we left because one of them had missed us while we where in the ICU visiting. It was just so amazing and very touching. If you are ever in an ICU for any significant amount of time, do go back and visit them, if you can, to say thanks. I can not tell you how much it means to those nurses. It was very wonderful.

Unfortunately, though, Michaela woke up sick on Tuesday morning, so we thought it best for me not to be around her for a couple of days, since my immune system was just coming back. So she and Chris went up to my parents while Natalie and I went to her parents. It was very sad not getting to be with my kids right away, since that is what I look forward to so much while in the hospital. But a couple days later she was getting better and my immune was even stronger, so we were reunited finally!

Most of last week I was feeling pretty awful and was also really depressed (partially just because of pain killer withdrawals, and partially because of too-complicated-to-explain emotional stuff). But by Friday I was feeling a little physically better and Tim, Nolan, and Nathan hung out with me on super short notice and totally and completely cheered me up more than I can describe!

So now I am on the road to full recuperation, we are looking for a place to live, and going to slowly get back to “regular life.” Wow. It is just so amazing. To think back to May when the doctors where informing us that the whole ordeal would take 6 months to a year of our life (if I survived at all) and wondering how that would even be possible! Well to put it very simply and truly, it was made possible by all of you!!! Praise be to God!!!

P.S. Remember details on a BIG party coming soon! If you have any suggestions or ideas, let us know!

**December 15, 2006**

[a note from nathan](#)

you may have noticed that this blog has been unavailable now and then over the past couple weeks. if you haven't, you've been lucky (or checking late at night).

truth is, aaron is just too popular...especially amongst those selling certain pharmaceuticals and offering online gambling. that's right, this blog is getting spammed. a lot. now, the spam blocker is catching all of the spam before the comments get published, but even having to deal with these illegitimate comments is putting a huge tax on my little server...so much so that the whole thing is shutting down as it gets overwhelmed.

unfortunately, i'm left with only one choice: i am turning off comments, at least for a time, on aaron's blog. fortunately, all the comments that exist currently will still be there. unfortunately, this means you'll have to communicate your love and affection for aaron and cothe old fashion way: by email!

sorry about the bad news.

- nstryker

## **December 23, 2006**

### [Merry Christmas!](#)

You shall call His name Jesus, for He will save His people from their sins. Matthew 1:21

What a difficult and amazing year this has been. As we celebrate the birth and life of our Lord Jesus Christ, we also celebrate the wonderful gift of life that God has given Aaron. We look back in surreal wonder to the day when the doctor told us Aaron had leukemia and it would take 6 months to a year of our life. But after many prayers, tears, drugs, and many, many days in the hospital, we have finished the journey and we are looking forward to a lifetime of remission! And so we praise God in a special way this Christmas and we thank you for the incredible love and support that you showed us this past year. You mean more to us than we can express. May your Christmas be greatly filled with the joy of Christ!

P.S. We want you to come to our \*God Smites\* party on Saturday, January 27! We do not have any other details yet, but please put it on your calendar because we really want you to come. Check back to this blog soon for the rest of the party details.

With much love,  
Aaron, Natalie, Michaela and Christopher Boydston

(acboydstons at junodot com)

Indeed, in our hearts we felt the sentence of death. But this happened that we might not rely on ourselves but on God, who raises the dead. He has delivered us from such a deadly peril, and he will deliver us. On Him we have set our hope that he will continue to deliver us, as you help us by your prayers. Then many will give thanks on our behalf for the gracious favor granted us in answer to the prayers of many. 2 Corinthians 1:8-11

## **January 12, 2007**

### [Party Details](#)

Come to a Praise God! party for Aaron Boydston...

When Aaron was in the hospital, a lot of people came to visit. On one Sunday, there were about 50 people there at the same time! We always said how much Aaron would love to be there visiting with everyone and that when he was better we would have a party to celebrate. Well, party time is here! Please join us for an evening of praising God for His goodness, celebrating Aaron's life and thanking you for your support. We really, really hope that you can come!

Who: You! All who want to honor God for the gracious favor He has granted us in Aaron's healing.  
Where: Ojai Wesleyan Church; 105 E. Topa Topa St., Ojai, CA; (next to Starr Market and the Ojai Library)

When: Saturday, January 27th

What: We will serve a buffet dinner from 4 p.m. until 8 p.m. Feel free to drop by at any point during this time for some fun, food and fellowship.

\*Please, bring a dessert to share, if you are able.

We can't wait to see you there!  
Questions? Email at acboydstons at yahoo dot com

## **January 27, 2007**

### [Battle 27 January, 2007](#)

[My dad wrote and read the following at the "Praise God Party." - Aaron]

“Except in the worlds of Nintendo, paintball, and the UFC octagon, battle is not something we generally choose to initiate. Battle is something we do when we are called. We join the battle not because we go about spoiling for a fight, but because we are called to fight. We join the battle when we are called to fight an enemy which, should we choose not to fight, would take from us that which we hold precious. We are here today to celebrate our victories in a war we did not seek, we did not want, and for which we did not plan. Our enemy came suddenly, and with awful violence sought to wrest from us that most precious; sought it not to elicitly enjoy it, but to wantonly destroy it.

We are here to celebrate with those who joined us in the battles; the few who could be here and the many who could not. We are here with deep gratitude for the warriors who stood together, closed ranks, and fought through the night. We celebrate our victories in this fight that we joined some 8 months ago. And we celebrate our recent season of quiet, of rebuilding, and of recovery.

During battle, there is no time to think; during peacetime, there is time to ponder art, science, and our place in the universe. During peacetime, we want a New Testament God; a God of mercy and compassion, for during peacetime we have the time to look inside ourselves and see our profound shortcomings and many failings. We know the depths of our failure to appreciate all that we have been given; we bow, and ask forgiveness.

But when we go to battle, we want the God of Abraham, Isaac, and Jacob. We want the God of the Old Testament Who rises up, goes before us, and slays our enemies. We want the God Who Smites.

Today, we pause, reflect, and we give thanks to the God who smites, to our God Who, in His great mercy, smote on our behalf.”

## Chapter 3 • Relapse • January 28, 2007 – April 10, 2007

### *The War Starts Over*

**January 28, 2007**

[Sunday 28 January, 2007](#)

Aaron never really went to sleep after the smite celebration Saturday night. For the last few weeks, a reasonably persistent level of overall discomfort, cold/allergy symptoms, insomnia, and more particularly in the last few days, nagging headache, has been addressed by a phamacopia of Dilaudid, Ambien, Benadryl, Sudafed and Vicodin (not all simultaneously). By 2 am Sunday morning, most of the boulderhaven household and guests had tired of watching Annalyse choose cosmetics and costumes for her video game character. Only Aaron remained faithful, helping her learn the game and extract her character from jams in cyberblivion. A midnight dose of Ambien did not seem to be working, so around 5 am, a second dose seemed reasonable. For the next 6 hours, Aaron was anything but reasonable. Wandering and stumbling around the house, talking to lamps and muttering slurred nonsense, it was as if he were sleepwalking or vacationing in pharmospace. Around 11, he finally went to real sleep. Natalie woke him a couple hours later and insisted that even if he was feeling O.K. and was now coherent, that he go to the Ojai Community Hospital ER. The CT brain scan ordered by Dr. Nelson revealed an ominous, quarter-sided spot toward front of the right temporal lobe. He called Dr. Paquette at UCLA, who said bring him to Westwood in the morning. Within the hour, a 29,000 WBC count with a high percentage of blasts elicited a second phone call to UCLA. "Don't wait until morning, go straight to the UCLA ER."

With scorn and brazen affront, the enemy has mocked our celebration.

**January 29, 2007**

[Monday 29 January, 2007](#)

The UCLA Westwood Emergency Room had been notified that Aaron was coming, so he got the VIP treatment: "Come right in, Mr. Boydston." Some time after midnight, he checked out of ER and into room 803. By 3:00 AM, he got probably the fastest MRI scan in history; down and back in less than 30 minutes. The idea of the MRI is to help determine what kind of blob is spotting the CT film: Tumor or infection. The blob, an oblate about 2.5mm X 3.0, is rather dense with distinct boundaries. It looks more like a tumor, but there is a kind of dense, ball-like fungus infection that the brain surgeon refers to as a "fungus ball" (pretty creative naming...perhaps to be expected from a brain surgeon) that mimics a tumor.

If the blob is a tumor, it will likely be addressed with cytotoxin: ie, chemo. If the blob is an infection, it will likely require surgery to scoop it out. If the blob is an infection, starting chemo may not be advisable, as the chemo will further reduce Aaron's immune system and give the infection opportunity to spread. But delaying chemo for long is not an option, as Aaron has gone from a clean bill of health just 2 weeks ago to 70% blast count and his first platlet transfusion of the year this afternoon.

A spinal tap is scheduled to help determine the nature of the blob, then postponed as there is some concern that if the blob is a collection of leukemic cells, removing some cerebrospinal fluid may disturb the cells and they might wreak havoc.

The day is spent with many doctors asking the same questions and proffering different opinions, but no decisions.

## **January 30, 2007**

### [Tuesday 30 January 2007 am](#)

Observing the medical decision-making process is akin to watching an amoeba eat. Somehow, the shapeless, amorphous creature oozes in the general direction of food, little by little surrounds the food and eventually the food and the amoeba become one. Around midnight, Aaron spiked a fever. The night doctor called to assess the fever confirmed that indeed a decision had been made late yesterday to begin induction. The decision had translated to orders, which effected hanging a third bag on the I.V. pole (joining the normal saline and some Arm&Hammer dealing with blood already too acidic). The New Year's first poison volley, Cytarabin, begins to flow at about 3:00 a.m. Dilaudid, Benedril, Decadron, Posaconazole, antibiotics, magnesium, phosphorus, and insulin are variously administered to address constant and growing pain, allergic reaction to platelets, Chemo side effects, fungus, bacteria, electrolyte imbalance, and blood sugar spiking at 200. No picc line has yet been installed; blood draws are getting more difficult and painful. Another MRI is scheduled for later today, and the on-again-off-again spinal tap has been on and off yet again. There is agreement, even without the spinal tap, that the brain blob is not an infection. It is a mass of leukemic cells that will be fought, along the the mutant blasts now filling his bone marrow, with poison.

### [Tuesday 30 January 2007 pm](#)

Dr. Paquette came by a little before sundown as a light rain began falling. We cheered him like a rock star. In the medical morass of uncertainty, Dr. Paquette brings, if not certainty, at least direction. And for now at least, the direction is clear.

For the next 6 days, Aaron will receive as much Cytarabine as he can tolerate. The side effects (like liver damage and cardiac failure) of all other possible established mutant poisons, such as Mylotarg and various anthrocyclines make them unsuitable.

When as many blood and stem cell mutants as possible are destroyed (hopefully enough to return Aaron to the state of remission [where our previous residency was a far cry from permanent]), a spinal tap (fancy name: lumbar puncture) will be performed.

Should tests on the cerebrospinal fluid reveal the need, poisons will be induced into the brain and its nervous system.

During the next couple months, while the poisons are laying waste as much of the enemy as possible, a more permanent solution will be sought: Stem cells from a donor old enough to enlist: enlist to fight terror from abroad, or enlist to fight terror from within.

More information will follow, much of which can be found at [www.marow.org](http://www.marow.org)

## **January 31, 2007**

### [Keep Trusting God \(by Natalie\)](#)

On January 10th, Aaron had a blood draw at UCLA that gave absolutely no indication of a relapse. Dr. Paquette said they tested for everything and all tests were negative. When we took Aaron to the ER because he was acting funny (on Sunday, January 28th), Dr. Paquette was completely shocked to discover that Aaron had relapsed. So, just hours after having our planned Praise God Party to honor God for the miraculous healing He did for Aaron, we find out that Aaron is again fighting leukemia. In fact, as we were praising God collectively last Saturday, the leukemia was returning. What are we to make of that? Didn't we ask God to smite the cancer and didn't it appear that He had



done so? What about the timing of the recurrence? Does any of this suggest that we should not continue to trust God for healing?

I don't know the answer to the many questions that pop into our heads about Aaron's relapse. But I do know that we are to continue to trust God for complete healing. For me, when I think about the events of the last year, I think immediately about the Israelites, do you remember them? God was concerned about the misery and suffering of His people in Egypt so He decided to rescue them by blessing them with their own land (Exodus 3:7-10). So, God busted them out of Egypt in a way that was so like His ways—completely not understandable to us. We wouldn't have come up with a plan like that: sending 10 plagues and having His people cross the Red Sea on dry ground. The Israelites saw the miraculous power of God but what happened next? They praised God for awhile but then started complaining, grumbling and doubting. When God brought them to Canaan, the land He promised, they sent 12 spies in to look around and 10 of those spies determined that it was impossible—God could never help them defeat the people living in that land. They went so far as to say they should have stayed in Egypt or died in the desert. They were untrusting and ungrateful and God did to them what they said that He would—they would die in the desert and not be allowed to enter in (Numbers 14:28).

So, I use the history of the Israelites to learn about how God works and what He wants. He wanted to rescue the Israelites and give what is good to them. He did that by His omnipotence. He did that in His own way and His own time. He lovingly cared for, protected and provided for His people all the way along. These are the things I have seen Him do for us: He rescued Aaron, He has protected Him, He has provided for us.

I also want to learn about what my response should be to God. The Israelites did praise God but they turned to distrust, contempt and ungratefulness. Even though we are weary and we don't want to be here, I REFUSE to stop trusting God. I am grateful for all He has done, I remember the miracles He has done and I know that He is still able to do the impossible. Just because this is taking a long time or it doesn't look like a good thing by human standards or this is not the way that we would expect God to act, that doesn't mean He is not working or that He is less worthy of our trust. I see Him working: His protection, His mercy and His provision are evident everyday. I personally believe that God was so pleased with our shouts of praise to Him on Saturday, that He decided to bring on the smiting. I believe God decided in His mercy to not drag this out for us but to finish the miracle that He started.

So, I ask you, please stand with us in trusting God and being humbly dependent on Him. Don't say He can't and don't say He won't. Don't question His goodness or His ability. Remember what He has done. Trust Him to do it and He will—Mark 11:24.

Update on Aaron:

Dr. Paquette said that the leukemia might not have ever been in remission. When Aaron had the two bleeds in his brain last May, some leukemic cells from his blood might have gotten into his brain and have been hiding out in there. Thus, producing the mass of leukemic cells that they found a couple of days ago.

He is on a high dose of chemo and will receive six days worth of it instead of four.

He had a high powered MRI today and the results should be back by tomorrow (I think).

We are looking at possibly doing an adult stem cell transplant for Aaron in a couple of months. On the international database of stem cell donors (which consists of 12 million people), there are only 2 possibilities of matches for Aaron. They will contact those 2 people and see if they are willing to be

tested further to see if they are true matches for Aaron. We are working on having an adult stem cell donor drive in Ojai on March 11th. It would require a simple blood test. For anyone interested, stay tuned for details and visit [www.marlow.org](http://www.marlow.org) in the meantime. That website is also helpful for anyone who would not be able to make it to Ojai or who is interested in donating now. You can find a list of donor centers or upcoming donor drives under “How to Help.”

Aaron is starting to feel pretty crummy-he is receiving his 4th dose of chemo right now. I am so proud of him. He has a good attitude and trusts God so much. He continues to be a trooper. I love him so much. He is amazing.

We appreciate everyone’s calls and stopping by. It is hard going from getting back to normal life to picking up immediately and coming down to UCLA indefinitely with only the clothes on our back. It is a difficult adjustment and everyone’s prayers, calls, visits, platelets, etc. are appreciated more than words can express.

## **February 2, 2007**

### [A Quick Update \(by Natalie\)](#)

1)Praise God! Aaron’s doctor said today that the mass of leukemic cells in his brain is getting smaller so that means the chemo is reaching it.

2)Aaron just finished his 8th dose of chemotherapy. He just became neutropenic (no immune system) today.

3)Today was also Aaron’s first day feeling really bad from the chemo.

4)Dr. Paquette saved the day again :) when he upped Aaron’s dose of Baclofen from 5 mg (the regular dose) to 20 mg (the hiccup dose). Aaron has been having what he calls the “hiccups from hell” since chemo started. They are just really strong hiccups that go on forever. Thank you God for every good thing!

5)We are gathering more details about the adult stem cell donor drive we are having in Ojai on March 11th. It looks like all that will be required is a cheek swab. There may be a fee involved but we are working on getting grants to cover the cost. It will be held at CLC after church. There will probably be another donor drive in Pomona during March. Please, tell your friends!

Thank you for your love and support! God bless you.

Praise our God, O peoples, let the sound of His praise be heard Psalm 66:8

## **February 6, 2007**

### [DONOR INFORMATION \(by Aaron’s mom\) and a super quick update \(by Natalie\)](#)

I’ve talked to the local National Marrow Donor Program recruitment specialist, Holly Collier, who has been very helpful. We are presently organizing several Donor Drives for Aaron. Soon we’ll be able to post dates, times, and places. Meanwhile, here’s some brief information:

1. Donors must be between 18-61 years.
2. It only takes a cheek swab (In some areas in the country, they do finger-pricks.)
3. There is a lab fee, but between grants and gifts, cost shouldn’t stop any donor. In some states, it’s free.
4. Aaron does not need marrow, but stem cells. A Stem Cell transplant is a lot like donating blood or platelets (which many of you have done already.)

5. Even if you are not a match for Aaron, you could save someone else's life by being in the donor bank.
6. If you are too young, old, or ill to donate, consider sponsoring a donor. Gifts of any amount can be sent to:  
NMDP; Attention: Holly Collier; 1231 E. Dyer Rd.; Suite 236; Santa Ana, CA 92705  
(On memo part of check: Donor Station 2, Aaron Boydston)
7. It's not hard to host a Donor Drive for Aaron. All you do is provide a location and about four volunteers. They do everything else, including publicity (custom fliers, speakers, etc.)! Call Holly, 714-800-1613
8. Aaron should be ready for a transplant in two months.

LOVE TO FAMILY AND FRIENDS, Anne

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\*\*\*Update on Aaron (February 5th): There hasn't been much new activity to report. He finished chemo on Sunday afternoon. Mostly, we are just waiting for his white counts to get lower. When this happens, they will do a spinal tap and also inject chemo into the spinal fluid to kill any leukemia that may be in the spinal fluid and/or brain. We have not received results on the EEG he had a few days ago which probably means they found nothing of consequence. He should be doing an MRI on Tuesday to see if there has been any change with his brain lesion. Please, pray that Aaron will be able to get some regular sleep. For the past few months, he has had a terrible time sleeping. While being in the hospital this last week, he has only been dozing off for 5, 10, 15 minutes at a time. Also, please pray that his nausea and fevers (which should be coming up soon) will be minimal. Oh, here's a big Praise God! Aaron's liver enzymes have been elevated on every blood test for the last few months—this indicates possible damage to the liver. Today, his liver enzymes were completely normal! Also, thank you to everyone who helped make my "hospital birthday" special on Saturday. I enjoyed visiting with everyone who came by! Aaron managed to get a beautiful bracelet for me even while confined to his hospital bed and Dad Boydston made "SMITE-zels" (pretzels in the shape of an S)!

[Psalm 27:14](#)

Wait for the LORD; be strong and take heart and wait for the LORD.

[1 Comment »](#)

## ***Eye Pain***

**February 7, 2007**

[The last 24 hours: Lots of Pain and No Sleep \(by Mom\)](#)

Yesterday evening, after the best nap he has had in days, Aaron's eyes started flooding with tears. An hour later, unbearable pain began in his left eye. After a sleepless night, six hours of exams and five ophthalmologists: Aaron has chemo-induced cysts on his cornea. The treatment: two kinds of eye drops (steriod and dialating), pain killers, and time. We're all tired, and Aaron continues to endure. Please pray that the excruciating pain he is in will be alleviated—it is so hard to see him hurt this bad.

I'm all worded-out, but in summary: Cancer Sucks but God is Good.

**February 8, 2007**

### [A Better Day! Praise God!](#)

Aaron's eye is so much better! His day of Eyeball Torture is over. He got a PCA pump that allows him to dispense his pain medicine himself. The pump has worked great since last night. He even uses less pain medication this way. The last MRI shows the brain lesion (sometimes known as the tumor) has shrunk significantly. And no fevers. So, let's hear a super, duper, big "Praise God!" I think Aaron still has some chemo-brain; Today, he and his IV pole took an unauthorized trip to the 10th floor. His get-away was ruined by a dizzy spell just outside the 10th floor elevator. It caused quite a stir. His nurses on both floors weren't happy. Nor were Natalie and I. His explanation: He needed some time alone. Well, that's reasonable...

There's been a lot of questions about the adult stem cell donation process. We are still gathering information. Once we have the big picture, we'll post more. Meanwhile, talk to friends and family, and pray for a match. We find that [www.marlow.org](http://www.marlow.org) answers a lot of questions. You can also call or email us with questions (acboydstons at yahoo dot com). For those of you who want to be tested but are unable to attend the donor drive, you can check [www.marlow.org](http://www.marlow.org) for a list of donor centers in your area (look under "How to Help"). People at the donor centers are very helpful in answering questions, as well. If you want to host a donor drive, contact us or your local donor center. It has been our experience that it is a super easy thing to do—the local donor center is doing everything for us. We appreciate your prayers and anything you are doing to help!

**February 9, 2007**

### [A Calm Day \(Mom and Natalie\)](#)

Today Aaron's eye pain is well managed, though he does have double-vision. After another eye exam, no one's too worried. Besides, he gets to see two Natalies and two Moms. His sleep deprivation is still an issue (a by-product of his meds). Because he is sleep deprived, his sleep pattern is off and he will often go to sleep in the middle of activities. Today, he fell asleep with a mouth full of lunch. Waking up with two-hour-old corn still in his mouth hasn't increased his fondness for hospital food. He dozed off while reading an eye-chart a few minutes ago. It's a happy sight to see Aaron sleeping (remember when we couldn't wait for him to wake up!). When he was in kindergarten he had the dubious honor of being the "Best Napper" in the class. Those of you who suffer from insomnia know that "If I Could Only Sleep..." feeling. On the other hand, Aaron's blood production has been on the sleepy side; he needed a unit of platelets and two units of red blood cells. Some fresh blood always perks him up. Thank you blood donors!

Today we met Holly Collier. She will be coordinating the Donor Drive in Ojai. What a delightful and giving person. Our good friends Gail Fletcher and Kris Wiggernhorn are helping to organize a drive in the Pomona area. Our cousin Cathy Korsant is helping out on the east coast. Many thanks to everyone on the Donor Team! Praise God!

It's 9pm and Aaron has developed a fever and chills in the time it took to write this. Pray for him.  
Love, Mom and Natalie

The Lord says, "I will rescue those who love me. I will protect those who trust in my name. When they call on me, I will answer; I will be with them in trouble. I will rescue and honor them. I will reward them with a long life and give them my salvation." Psalm 91:14-16

### ***Heart Scare***

**February 10, 2007**

### [Saturday 10 February 2007 Maybe not quite so Calm](#)

When you decree a day to be calm, it may be that you decree before the day is done. Or you may decree while thinking, like a good Orthodox Jew, that the day is done when the sun goes down. At the Westwood UCLA Medical Center, the day is done at midnight. About an hour before which our previously decreed calm was revealed to be that which precedes the storm.

Somewhere into the day's second bag of transfusing red cells, a rash appeared around Aaron's neck, chest, and shoulders. Tight throat, mounting chest pressure and intense constant pain through the chest and into the back. The heart rate climbs quickly to 130 beats/minute.

Immediately, the transfusion is discontinued and the bag of blood is whisked away for analysis. Benadryl is quickly administered to squelch any possible willy-nilly histamines produced in allergic response. Nitroglycerin, whose explosive properties tamed by diatomaceous earth provided the foundation for Alfred Nobel's fortune and the prize money over 100 years later for the scientists who discovered why the workmen at Alfred's dynamite factory traded chest pains for headaches, was given in the event that a heart attack was in process. A surge of pondering and questioning doctors, a bevy of technicians with probing machines, and nurses to ply the better living through modern chemistry prescribed by the doctors kept things hopping until about 3 am, by which time Aaron has napped a bit and woke feeling much better, continuing where he left off before the night began with a computer folder tutorial for Mom.

By early dawn, Aaron has been moved to "his" room, the familiar Room 1040, whose more spacious quarters are occupied by additional monitoring equipment. A few hours later, the alarming bumps on the electrocardiogram reside, and with them discussion of yet another move...a move we are glad to avoid....a move to the cardiac intensive care unit.

Through the daylight hours, Aaron intermittently feels O.K. and lousy, chest pains come and go, fever goes up and down but never out, the heart rate vacillates between 120 and 140, and the diagnosis candidates are winnowed by the medical election primary process down to 2 choices:

A small bit of heart tissue has died due to lack of oxygen (fancy word: infarction), AKA, heart attack

The bag that holds the heart is inflamed (fancy word: Pericarditis).

Heart Attack takes an early lead, but as the sun sets Pericarditis is pulling ahead.

In all the excitement, we nearly forget that we will vote for neither candidate: they are both allies of the enemy.

## **February 11, 2007**

[quick note from nathan](#)

i've turned back on comments for the last few posts. thanks to a solution from lynn watson forwarded to me by ken, we should be in business and safe from spam.

[2 Comments »](#)

### [Sunday 11 February, 2007](#)

Pericarditis, taking a commanding lead in the poll returns as last night fell, seemed a sure winner. Until Dr. Lee (who answered the phone last May when Dr. Williamson called him in the middle of the night from Ojai) walked in a little before midnight with a frown.

The enzyme Tropanin, observed in Aaron's blood about a hundred times too high and rising, is an unequivocal indicator of damaged heart muscle. Overall, Aaron's heart is functioning on the low side

of normal, but toward the bottom rear is a section that, between the EKG and ultrasonic echo cardiogram, is observed to be considerably less than adequate....perhaps damaged.

So it looks like Heart Attack is back in the race. And Heart Attack no longer looks like a wimpy little also-ran, but a major heart-stopping threat. Indeed, if head cardiologist Dr. MacLellan were not looking at and talking with a feeling-pretty-good Aaron, he might, based on some of the test data, be preparing to unclog a major blockage in a coronary artery.

By noon, additional blood tests, EKG's, and echo cardiograms convince both the cancer doctor team and the cardiac doctor team that a major artery blockage must be immediately confirmed or eliminated from contention. So the phone calls go out to the on-call cath lab team, interrupting them from various Sunday pursuits. Risks are explained to Aaron (normally very low risk, but in Aaron's low platelet condition somewhat higher), consent forms are signed, and he is wheeled down to the cath Lab in the B basement for a coronary catheterization and angiogram. Dr. Lee (a different Dr. Lee), still in church when his call came, assures us that none of the team is annoyed at the interruption of their Sunday afternoon; in fact, Dr. Lee prays for success on Aaron's behalf.

The cath goes without a hitch, the angiogram images reveal no blockage, and the swarm of perplexed, pondering, and pontificating doctors who for 2 days have been drawn to Aaron like summer moths to a Louisiana porch light, disappears without a trace.

We share their palpable relief, yet wonder about the anomalous data and if Pericarditis, now a seeming shoo-in candidate, has a running mate.

[4 Comments »](#)

**February 13, 2007**

[Update \(by Natalie\)](#)

When Aaron began having chest pain on Friday night, a true lesson began in not trusting in the wisdom of men but in the power of God. There has been a real uncertainty and confusion amongst the doctors as to what happened to Aaron's heart that persists even to this moment. Friday night was honestly pretty scary when they switched rooms on us in the middle of the night so that Aaron could be connected to a heart monitor. We really had no idea what was happening then. On Saturday morning, the oncologists came in and said they thought it was a heart attack. The cardiologists came in and said they thought it was swelling. Sunday morning, the two groups reversed their positions. What both groups agreed on was that whatever was happening, Aaron's troponin level was so high that it indicated the heart had taken a hit and suffered some significant damage. Since the cardiologists didn't want Aaron to be having a major heart attack under their noses, he had an angiogram on Sunday morning. There were several risks involved in having the angiogram but you all trusted God together (thank you for your prayers!). God heard and answered our prayers in an amazing way. The angiogram went completely without complication and God sent Dr. Lee, a brother in Christ, out to meet us. Before he started the procedure, he gave encouragement and helped strengthen our trust in God. So, after the angiogram showed no major blockage (Praise God!!!), on Monday morning the doctors all came in suggesting the problem was an infection that caused inflammation. As of Monday morning, they were also sure that the damage to the heart had stopped occurring. Today, the doctors are coming in saying the problem with Aaron's heart was probably more like a heart attack that occurred when micro-capillaries were blocked with something like leukemic cells or a sludging of blood. But, I very much expect the leading theory to change by tomorrow, if not this afternoon! During this whole time, I have been thinking about Peter when he wanted to walk out on the water to Jesus. All the conflicting theories and test results that keep coming are just like the waves that Peter saw all around him. Peter should have kept his eyes

on Jesus and not on what was going on around him. That is what I have been trying to do through this stormy sea that we are walking on right now. I am trusting in the power of God and not the “wisdom” of the doctors or the test results. God has been so good to us thus far. I have never seen Him do anything other than what He says in His word. He is most worthy of our trust.

Thank you, thank you, thank you to Nathan Stryker and Lynn Watson for turning the comments back on. You both are geniuses!

If anyone tried calling the number we gave for Holly Collier (regarding stem cell testing) and did not get a hold of her, it was because we posted the wrong number on the February 6th post. The real number is 714-800-1612. She will be happy to help anyone who has any questions regarding stem cell testing or hosting a stem cell drive.

Thank you for your continued prayers. Things to pray for specifically: repair of the damage to the heart, no further complications while Aaron has no immune system, wisdom for the doctors regarding a spinal tap/chemo injection into spinal fluid, strength to be here—it’s hard. Praises: Aaron is sleeping better, he is feeling better, they eye pain and chest pain have been reduced to a mild discomfort, the problem with his heart could have been way worse, his fever broke Saturday night and hasn’t been back since!, that He sustained us through a fearful time. We love and appreciate you all.

Give to the Lord the glory he deserves! Psalm 96:8

[2 Comments »](#)

## **February 14, 2007**

[My First Walk \(by aaron\)](#)

Last night, I went for my first walk as a “heart patient!”

Last time I was up and about was a week ago last night, just before my eye started bothering me (which may have been the start of my heart problem, or just coincidental). It seems like ages ago, it has been such a scary 2 weeks. But the walk was very nice. I went maybe 30 yards, which was over doing it a little. I can not describe the very-strange tiredness that stems from an injured heart. It is just weird. I got back to my room and felt a lot better only after a few minutes of lying down.

God bless you all!

[5 Comments »](#)

## **February 15, 2007**

[This Is Spinal Tap \[Day\] \(by aaron\)](#)

Today, the doctors will insert a needle into my spinal cord, suck out some fluid (for testing) and spit in some chemotherapy. This will give the chemo a chance to reach an area it normally can not get to from the regular flow of blood. It sure does not sound pleasant, but it should not be too bad.

Also getting platelets today, which means I am incredibly, super duper drowsy right now because of 50mg of IV benedryl.

UPDATE: Yet another theory! Dr. Paquette stopped by and lent his thoughts as to what happened. He thinks the unusually high dose of chemotherapy caused the problem with my eye and caused the lining of my heart to get inflamed. I prefer that he is correct here because his theory involves little to no long term heart damage! Praise God!

[7 Comments »](#)

## February 18, 2007

### [Sunday 18 February 2007](#)

White cells re-appear in his blood as the last of Aaron's hair disappears from his head. All systems seem to be returning to normal, and the weaning process from heavy pain killers is beginning. Maybe just a little too fast.

The dreaded spinal tap headache never materialized on Friday. Maybe it was just slow coming, as Saturday is a different story. A splitting headache and nausea dominate the day from early until sunset. So severe is the headache that another head CT scan is ordered.

Only good is seen in the scan; the tumor, 3 weeks ago the size of a robin's egg, has shrunk to less than ½ inch across; it's now a medium size hummingbird egg, though one even Hitchcock could not have imagined a bird so perverse would lay.

Today Aaron is better; his white blood cell count is stretching for the low side of normal. Dr. Glaspy declares neutropenia is past. Normally, this would indicate a change of cuisine, but tomorrow being President's day, a menu change from special low-bacteria hospital food to normal (though not stated on the menu, we assume that would be high-bacteria) hospital food is not possible.

A couple days of more weaning, and Aaron may qualify for a few days beyond the purvey of the hospital kitchen.

[1 Comment »](#)

## February 21, 2007

### [PAINFULL, FRUSTRATING, & PAINFUL \(by Aaron\)](#)

That pretty much sums up this last hospital visit (well, other than God's incredible goodness, which really does far supersede all the crummyess!).

For me, this last visit was reminiscent of my very first stay of May/June/July 2006. Thankfully, it was ONLY reminiscent, though, as the actual events were quite different and not nearly as drastic. But still, the underlying pinnings were there: it was scary, painful, and I even lost a little bit of time, though waking up a few hours later wondering where I am is A LOT different than waking up SEVERAL WEEKS later wondering where I am.

Of my 5 lengthy hospital stays so far, this last one was actually the second most painful. The most painful was, of course, the first one (and by a long shot!). This last stay was also very frustrating. I do not want to explain this too much b/c it mostly entails talking poorly of some of the doctors, nurses, and staff and I would just rather not do that. So let's just leave it this: the wrong ingredients kept coming together and getting prepared, cooked, and served in a bad way. I have no doubt I even contributed here and there! The result that made it to the table was often a big plate of frustration and it was always very painful to eat it.

Anyway, we were discharged yesterday! We have numerous immediate follow-up things to do, so we will stay down here at the Tiverton (right across the street from the hospital) for at least a week before marching back to Natalie's parents, who have continued to graciously open their home to us, the homeless Boydsons. Please pray for my pain condition: that I will be able to wean myself off of the narcotics while controlling what pain I do have and not experiencing horrible withdrawals.

God bless you all so much!!!

[11 Comments »](#)



## ***Super Short Discharge***

**February 22, 2007**

[Thursday 22 February, 2007](#)

Yesterday may be in the running for the Guinness Book of World Records as the shortest discharge of a person owning both Xbox 360 and Nintendo Wii. A fever, actually, “Fever”, one of the demon legion so named, returned with a vengeance, annoyed that its diabolical ally seemed to be getting, however temporarily, trounced.

Cold water, ice, and Tylenol could not seem to effectively reduce the fever much below a delirious 104F, which had Aaron talking intermittent gibberish for hours.

So, on the order of Dr. Paquette, back across the street to the ER we go for the second time in 4 weeks.

The PICC line is removed, yet more antibiotics consumed, and the hunt is afoot for the invaders. After languishing in considerable pain for several hours in the emergency room, Aaron is wheeled to the 5th floor and into a room whose bathroom was the scene of a post-Katrina vacancy. A leak had rendered the walls a curious texture, and they appeared to be hosting colonies of mold. A fine empty room on our good old 10th floor has been rendered uninhabitably leaky by the first real Southern California winter storm that set upon us as the invaders were setting upon Aaron.

Eventually, Room 809 offers refuge from both fungus and deluge; the fever comes down somewhat. In the event that there may be some insidious infection lodged in the spine, the second spinal tap in a week is performed.

It has been a hard day.

[3 Comments »](#)

**February 23, 2007**

[Friday, 23 February 2007](#)

“Meningitis” is an ugly word. But what choice is there to describe an inflammation of the sac-like membranes that enclose the brain and spinal cord when those membranes are called “meninges”? And what choice have we when the doctor, having bonked Aaron on the head and noting the sharp pain that shot from the head into the extremities, declares the diagnosis unequivocally? It certainly fits with the headaches, intermittent confusion, delusions, and fevers topped off with intermittently debilitating stiffness and pain in the back, neck, and various muscles.

Unlike pericarditis, whose cause is generally some unknown microscopic bug, meningitis is usually caused by identifiable bacteria or virus. Thus far, none of the usual suspects have been identified in the cerebrospinal fluid (CSF) sucked out in last night’s spinal tap. But there are any number of exotic causes, among them leukemic blast cells, which do not appear present among the abnormally large number of leukocytes present in the CSF. For this we are relieved and grateful.

Dr. Paquette suggests this most recent big word added to our vocabulary by Aaron’s penchant for new maladies may be yet another consequence of the very high cytarabine dose.

Aaron’s return to lucidity, his reduction in pain to an easily managed level, a move to the much nicer room 808, and Fever in full retreat put us all in a much better mood, despite having to learn such an ugly new word.

## ***Excruciating Pain***

**February 24, 2007**

[God sure does mean what He says! \(by Natalie\)](#)

At 2 a.m. last night, Aaron started feeling the worst pain he has ever felt in his whole life. If you have never seen someone you love in excruciating, agonizing pain which is so bad that it elicits continuous moaning and sobbing, then thank God right now. We had another sleepless night because of this pain that could not be touched by the amount of medication they were willing to give him. After a couple of hours of this, we stopped everything and we prayed that God would relieve this severe pain. We trusted Him together because that is what He says to do in His word: “Call unto Me in the day of trouble; I will deliver you and you shall glorify Me! (Psalm 50:15). We are told to trust and expect deliverance throughout the whole Bible. After we did that, immediately Aaron’s pain was relieved. But, it was relieved in a strange way. It was as if his pain had hit its absolute peak and his body had shut down the pain. However God chose to accomplish this, it was amazing. Aaron went from writhing around in the bed whimpering to sitting at his computer and reading [www.engadget.com](http://www.engadget.com). It was absolutely incredible. So, we are glorifying God for this miracle He did for us. Believe what He says in His word and trust Him completely.

[6 Comments »](#)

**February 26, 2007**

[Sleep, near discharge, please pray \(by Aaron\)](#)

I do not even know how long it has been since I have gotten a good nights rest. At least a few weeks. But last night I DID! It was absolutely wonderful. Praise God!

The doctor said I may be discharged [again!] as early as tomorrow. What this means is they want me out of here and will do everything they can to give us the boot. But there is always a chance it may take an extra day.

I would be a lot more excited about this except that I am still in a lot of pain. Even on a high dose of pain meds, I can barely walk (hobble) a few feet before I have to sit down because of the pain. The doctors think that this is simply a part of meningitis and will go away slowly. If they are correct, great! I am concerned, though, that there may be something else, like a pinched nerve, that needs to be addressed.

I have a special prayer request: NewLeads (my employer who is patiently waiting for me!) is heading into its “busy season.” I desperately want to contribute and think this should be possible, we will just need to be creative in figuring out how. So please pray that my bosses and I can come up with ways that I can do a little work!

God bless you all so very, very, very much.

[4 Comments »](#)

## ***Discharged, THEN Pain Relief***

**February 28, 2007**

[‘Tis So Sweet to Trust in Jesus \(by Natalie\)](#)

Thank you, God! Last night, we found out we were to be suddenly discharged. Within an hour, we were out of the hospital room. This was a scary thing because, at the time of discharge, Aaron could

not walk because of this mysterious pain he has been having for the last 2 weeks. What was even more scary was that Aaron was having a flare-up of pain each night. These flare-ups were horrible! He would writhe in pain, moan, cry for hours until a doctor would OK enough IV pain medication to bring it under control. Aaron was getting so much pain medication because of the tolerance to it that he has built up over the last nine months that several doctors said it would kill a normal person. With Aaron going home, we would not have access to this IV medication which was the only thing that ever brought relief. The thought of being at “home” when one of these flare-ups occurred was too much for Aaron to bear and he began sobbing upon hearing the news about discharge. He told me he was afraid. I said that what we were going to do was to trust God with this seemingly impossible situation. After all, what He can do is so much better than any pain medicine that they could have given Aaron. Sometimes, when there is a problem we have to deal with, it isn't easy to remember to trust God first. But, we remembered and we decided that we were going to do that. We prayed together and then began calling as many people as we had time to call before packing up and leaving. Many of you probably got a prayer chain call from someone! :)

So, check out what happened. It's awesome. Aaron was wheeled out to the shuttle that brought us over to the Tiverton. He could not put any weight on his left leg at all. The driver of the shuttle had to help Aaron get up and down the steps of the van. I wheeled him to our room and he made it into the bathroom using a walker. He decided to try to take a hot shower. Bam! God answered our prayers. The hot shower did something. All of the sudden, Aaron could move his left leg up and down and put weight on it! He immediately started walking around, too. We thought the shower would have a short-term effect but it didn't. And, do you think Aaron had a flare-up of pain last night? No, he didn't! God is so good. For the first time in over a week, Aaron did not have to experience hours of excruciating pain throughout the course of a day. He still is experiencing pain but it is controlled pain which makes a BIG difference.

Today, Aaron had an appointment with his primary care oncologist. Dr. Paquette said it seems like what caused all of this back pain was an allergic reaction to the chemo that was shot up through his spine. What it was exactly that happened will probably never be known. Some suggested theories: chemical meningitis, arachnoiditis, infection, inflammation that compressed a nerve. Whatever it was, God is healing and we are thankful to be out of the hospital. We are scheduled to go back to the doctor's office in one week to get a (different type of) chemo sent up Aaron's spine. We will attempt to leave in the morning for Ojai. We also got an update on the search for an adult stem cell match. One of the two possible matches for Aaron did not match. So, we have one person in the world that could possibly be a perfect match and several that would possibly be a slight mismatch. No worries. Jehovah-Jireh: God will provide. Mom Boydston is still gathering information on the upcoming stem cell drives. She promises to post soon.

Thank you to all who continue to pray for us. Thank you to those who specifically prayed about last night. Thank you for sharing in our joy. Thank you for glorifying God with us for all the miraculous things we have seen Him do. One of our friends was visiting last night and reminded us that God loves to show mercy. That's amazing to think about. Thank you God for showing mercy.

#### Psalm 116

I love the Lord because he hears my voice and my prayer for mercy. Because he bends down to listen, I will pray as long as I have breath!...I saw only trouble and sorrow. Then, I called on the name of the Lord: “Please, Lord, save me!” How kind the Lord is! How good he is! So merciful, this God of ours! The Lord protects those of childlike faith; I was facing death, and he saved me. Let my soul be at rest again, for the Lord has been good to me.

POST UPDATE (BY AARON) It is so great to be able to walk again!!!! PRAISE JESUS!

[5 Comments »](#)

### **March 1, 2007**

[Get Your Cheeks Swabbed Here!](#)

Here's some upcoming stem cell donor registration drives. If you can't be a donor, consider sponsoring someone! We are in need of sponsors! We would hate to see the fee keep any willing person from donating. Call Anne at 646-0740 (the area code is 805) or e-mail: boulderhaven @ sbcglobal . net (remove spaces when emailing)

At the stem cell donor drive, you will fill out paperwork and get your cheeks swabbed. Your name will be added to the National Stem Cell Donor Registry. If you happen to match Aaron or anyone else in the future, you will be asked to do further testing (a blood test). Should you closely match someone in need, donating stem cells is like giving platelets. The likelihood that you will even be called to take the second step of further testing for anyone in need is very, very slim.

WED, MARCH 7 Pomona 1:30-7:30

Pomona First Baptist Church

586 N. Main St., Pomona

Call 909-629-5277, ex.8081 to schedule time.

Tissue typing fee: Free

(City of Hope is picking up the tab so they would love it if you chose to donate blood that day.)

SAT, MARCH 10 Santa Barbara 10am-2pm

Christ Presbyterian Church

36 E. Victoria St., Santa Barbara

Tissue typing fee: \$52 (grants available)

SUN, MARCH 11 Ojai 12:30-4:00

Church of the Living Christ

190 E. El Roblar Rd. Meiners Oaks 805-646-1296

Tissue typing fee: \$52 (first 80 people, \$25)

\*\* If you're short on funds, come anyway! We have sponsors!

Donors must be between 18-60 years, and in general good health.

\*\* FREE tissue typing for all minorities. (Hispanics, African Americans, Asians, etc.)

If you have any questions, visit [www.marlow.org](http://www.marlow.org) or feel free to contact any of us Boydstons!

[2 Comments »](#)

### **March 5, 2007**

[Happy 30th Birthday, Aaron!](#)

I love you, sweetheart!

[8 Comments »](#)

### **March 8, 2007**

[Moving Quickly Towards Transplant \(by Aaron\)](#)

We are currently in Ojai, staying with Natalie's Parents.

I had a barage of tests yesterday down at UCLA, very tiring. Also had more chemo injected into my spine; feeling pretty nauseous and bad overall.

The transplant should start in a couple of weeks. Dr. Paquette is leaning towards using stems cells from an umbilical cord because the one remaining adult donor did not match closely enough. Dr. Paquette wants to get this done as soon as possible. Please, pray for a great amount of wisdom from God for Dr. Paquette—there are a lot of decisions to be made. A transplant is a very serious ordeal.

Next week I should get another shot of chemo in the spine and a bone marrow biopsy in order to know exactly what the status of the leukemia is.

Thank you to all who have been organizing the stem cell drives and to all who turned out for the drive in Pomona. It would be such an amazing blessing if a match came from one of these drives for someone in need. There are two more drives coming up: March 10th in Santa Barbara and March 11th in Ojai. For more info on these two drives, scroll down a couple of posts.

For I know the plans I have for you,” says the Lord. “They are plans for good and not for disaster, to give you a future and a hope.” Jeremiah 29:11

[7 Comments »](#)

**March 12, 2007**

[swabbed! \(posted by nathan\)](#)



[Stem-cell Drives: Ahoy Swabbies!](#)

Thanks to all who helped by organizing, sponsoring, praying, and swabbing! We gathered 222 tissue samples from the three drives, plus many more from out-of-area cousins, uncles, aunts, and friends! The tissue-typing lab will be expediting these last batches. Pray for the lab crew! Another 300 swabs were expedited today for a little boy with the same time crunch as Aaron. We have done everything we can on our end. The rest is up to Aaron's body, his medical team, and the Lord (not necessarily in

that order!) Aaron is home, recovering from Wednesday's second dose of spinal chemo and not as nauseous as earlier this week. Again, thank-you, and lots of hugs to all! love, Aaron's family

## **March 15, 2007**

### [Doctor Visit \(by aaron\)](#)

Yesterday, Natalie and I traveled down to UCLA for some more tests and procedures to bring me closer to starting the stem cell transplant.

Thankfully, I did not get another spinal tap with chemotherapy. Although they usually affect the patient very, very mildly, the spinal tap I got last week hit me hard. I was extremely nauseous and felt really awful all last week. So I was filled with joy when Dr. Paquette said we would not do another one!

To balance the day out, though, I did get a bone marrow biopsy. Basically, they drill into the bone and remove a small cylindrical sample of the bone about the size of a skinny, very short toothpick. The drilling is really a slow grind and as Dr. Paquette was grinding away, I quickly remembered why I do not like bone marrow biopsies! They are miserable and in a very unique way which makes it worse. It is hard to describe but just imagine someone drilling/grinding into your bone. You should be cringing right now and mad at me for making you think about it! I do not know how long it will be sore for, but the pain has let up a little bit after 24 hours.

The current estimate is that I will begin the transplant in about two weeks.

God bless you all so very much!

[2 Comments »](#)

### [Birthday Party!](#)

PLEASE COME TO MY BIRTHDAY PARTY!!!

When: This Saturday, March 17

Time: 2 – 10 pm Come all-day or anytime; I am planning on being there the whole time, though I will probably be taking little naps here and there!

Where: 1624 Foothill Rd.; Ojai, CA; USA; Earth

What: Just a good time together and lots of video games!

Who: Everyone is invited! To be frank, I did not have enough energy to send out invitations, so I am counting on ya'll to spread the word and invite anyone you think may want to come. Thanks!

Prayer: We will be having a special time of prayer at 8:00 PM because I will be starting my stem cell transplant very soon. If you are unable to attend but would like to "pray with us," please do so! We will start praying at 8:00 sharp, so if you also pray at 8, you can be sure we will all be praying together in the Spirit.

God bless you all and I hope to see you on Saturday!

In His Grace,  
Aaron

[1 Comment »](#)

## ***Real Remission***

## **March 21, 2007**

### [Sweet, Sweet Remission!](#)

Dr. Paquette called me today but got my voicemail. His message began with the words, “since I am calling with good news, I can leave it as a voicemail...” The results from my bone marrow biopsy (did I mention that I do not enjoy those?) came back and I am in remission! Praise God!!!

Now before you get too excited, though, being in remission does not mean too much at this point. While it is a VERY GOOD thing, it does not change treatment in any way and may or may not affect the long term outlook of the situation. The main thing it does (as far as I understand) is produce a much better environment for the stem cell transplant to take place. And it is wonderful and encouraging just to hear the words, “In remission!”

Also, I had an absolutely wonderful time at my birthday party. First of all, I was able to attend! And for the whole day, to boot. Many, many thanks go out to so many of you for coming, or praying with us, or just sending a birthday greeting, and for some presents too!

I continually thank God for your love and support.

[2 Comments »](#)

### **March 23, 2007**

#### [James 5:13-18...The Power of Prayer](#)

Aaron will begin 6 days of brain radiation this Monday, March 26th. He will be admitted to the hospital on the following Monday, April 2nd. Once admitted, he will receive 4 days of Total Body Irradiation followed by 2 days of strong chemo. He will then get a day of rest. The following day, he will receive his new stem cells. It will take up to 30 days for the stem cells to engraft.

We have “called for the elders of the church” to lay hands on Aaron before he begins his stem cell transplant. This will take place this Sunday, March 25th, at Ojai Wesleyan Church at 3:00. Anyone who wants to attend is invited! Hopefully, we will be having representatives of other churches in the valley participate in the laying on of hands. We would love to see you there if you want to participate in this time of prayer that is very important to us! After this event, we will leave for UCLA and remain there until the transplant is over.

Specific prayer requests: That the stem cells will engraft and not be rejected; for protection from the many dangerous and severe side effects; for protection from infection; for wisdom for the doctors and nurses; for strength for all of us; for God’s perfect timing as He is orchestrating every single detail; that God’s mighty power will be seen, recognized and turned into praise from all who witness what is going on with Aaron. We are fully relying on God for healing. We expect to see Aaron completely healed and are waiting (as) patiently (as we can) on the Lord for this! We acknowledge the miraculous healing that God has already done and we know He is faithful to complete what He has started. Thank you for your continued love, prayers and support. Be prepared to be amazed by what God is going to do in the next few months!

“We’ve come this far by faith, leaning on the Lord, trusting in His holy Word, He’s never failed us yet!”  
Albert A. Goodson

[6 Comments »](#)

### ***Lots a’ Radiation***

### **March 28, 2007**

#### [So Far, So Good... Not! \(by aaron\)](#)

I had my third round of brain frying today. After my first brain cooking on Monday, I was very tired and slept most of the day. Tuesday brought a very sore jaw, like someone punched me, and a not-too-bad headache. Today I woke up hurting all over, not too bad, but enough that I was not up to walking the 10 minute trek to Dr. Paquette's office, so Natalie wheeled me in a chair.

The mass in my brain has actually grown, so it is good that we are not wasting any time moving forward with treatment. Time is one of the big advantages of using the cord for the transplant. Using a person would end up taking a few more weeks which could be very bad at this point.

Anyway, overall, I am not too bad, which is good b/c I am not supposed to be too bad yet but after the full body radiation (which starts on Monday or Tuesday), it is expected that I could be really miserable. But hey, no big deal. The important thing is that I survive it and that has already been settled! Praise His name!

[7 Comments »](#)

**April 3, 2007**

[Here We Go. \(by aaron\)](#)

My first full body radiation is today so my stem cell transplant is officially starting! If I said I'm not anxious, I'd be a liar. If I said I'm not scared, I'd be a liar.

But, "Do not be anxious about anything, but in everything, by prayer and petition, with thanksgiving, present your requests to God." (Philippians 4:6) and, "...perfect love drives out fear..." (1 John 4:18).

"...join me in my struggle by praying to God for me." -Romans 15:30. Thank you all, THANK YOU ALL, THANK YOU ALL for doing just that!!!

So without further ado, here we go... actually I am starting right now!!! As I write this, they are informing me that I have to stop typing to immediately go down to radiation.

[8 Comments »](#)

**April 4, 2007**

[Wednesday Update \(by Natalie\)](#)

Aaron completed his first 2 days of Total Body Irradiation today. He has 2 more days of radiation, then 2 days of chemo and then a day or two of rest. His stem cells are scheduled to be given on April 11th. So far, Aaron is doing OK. He has been well enough to watch TV, eat, work on his computer and display his usual witty character. Praise God!!! The only issue, so far, has been that he is having a very rare auditory effect from the brain lesion. Aaron has been experiencing a strange replaying of sounds. For example, he listened to a voice mail and put the phone away. But, he kept hearing the voice mail replay in his head. It is not like an echo because he can hear full sentences repeat and the problem constantly occurs (as opposed to a few words repeating at the end of a sentence). Also, sound is modified in such a way that when he hears conversation, voices sound the same without any inflections. Right now, he reports that he hears the HEPA filter going and a replay of the HEPA filter at the same time. A neurologist came to see Aaron because of this. He said that he reviewed Aaron's case and recent auditory problems. He confessed that he was skeptical at first because he had never seen or heard of a patient with these type of symptoms. So, did some research. He found only 10 reported cases of these "auditory seizures." All 10 of these patients had a lesion in the right temporal lobe, just as Aaron does. Honestly, the neurologist seemed very excited and interested in what Aaron described. He probably wants to write a paper. :) The neurologist said that it is treatable—they will just increase his anti-seizure medication.



We had to send the kids to my parents' house because Christopher got a high fever on Monday. Dr. Paquette did not like hearing that Aaron had been around Christopher all weekend—he started Tamiflu as a precaution. In addition to praying for Aaron, please pray that the kids will both be well and able to come back down soon!

We welcome your calls and visits! Thank you for all of your prayers...it really means a lot to us that you are interceding our heavenly Father on our behalf. I know a lot of you have given us special Bible verses in the past. I have written down most of them. I'm typing them up, putting them on pretty paper and then hanging them on the wall. So, if God shows you a neat verse, post it in the comments section or email us. I'll put it on the wall! Much love to you all!

“We will come back to you...THE LORD WILL PROVIDE!” Genesis 22:4,14

[7 Comments »](#)

**April 6, 2007**

[Good Friday \(by Natalie\)](#)

Aaron finished his Total Body Irradiation today! He is still feeling O.K.—Praise God! There has been a little bit of a change in his chemotherapy plan. Because he is receiving the stem cells from a cord, Dr. Paquette has decided to use a chemo drug called fludarabine instead of cytarabine. He will also have his chemo infused over 3 days instead of 2 days. He is still scheduled to have his “3rd birthday” on April 11th. (They call the day you receive your stem cells DAY ZERO or your SECOND BIRTHDAY but because Aaron already has a second birthday [when he was saved], we are calling it his 3rd birthday!)

Christopher is feeling better but last night, Michaela got sick. That's OK: the sooner she gets sick, the sooner she gets well, the sooner they can come back!

A very special “THANK YOU!!!” to everyone who has made the long drive out here to donate platelets. You all are amazing!

Sarah Tribble posted a comment on March 31st saying “I pray many times a day that this whole ordeal will be a lot more comfortable than you anticipate it to be.” God answered her prayer in an amazing way! We all expected Aaron to be miserable when his radiation began. But, we finished radiation today and he is doing way better than we ever expected at this stage. It's been 4 great days—days that we had anticipated to be horrible. Four days is a long time, too! So, thank you Sarah, for letting us know you were praying specifically for us in this way. It is great to know what all of you are praying so that we can see all the amazing ways God is answering prayers! Keep praying that he will be more comfortable than expected, that he will stay safe from germs, that his body will be protected with no scary complications from the treatment and that the new stem cells will engraft perfectly. We are fully trusting God to give us all of these things! Much love and thanks to all of you!!!

“My old self has been crucified with Christ. It is no longer I who live, but Christ lives in me. So I live in this earthly body by trusting in the Son of God, who loved me and gave Himself for me.” Galatians 2:20

[3 Comments »](#)

**April 8, 2007**

[Sunday, 8 April, 2007 \(EASTER SUNDAY!\)](#)

The Easter Sunrise finery donned this morning by Jisook did not include a hat. Blue rubber gloves and an ankle length matching blue smock covering her nurses garb were the only extra accoutrements protocol required as she hung Aaron's Easter Morning bag of poison. Fludarabine and Cyclophosphamide will finish the job begun by last week's radiation.

Radiation damage depends on both dose and frequency. Even a professional bull-riding octogenarian and determined hypochondriac would be hard pressed to acquire 70,000 chest X-rays over a lifetime; all of which might not be as fatal as the occupation. But for all that radiation having been sprayed through Aaron's body last week, he is doing remarkably well. A very dry and slightly sore mouth barely dent a cheerful apparent well-being that belies the damage inside. If last week's radiation exposure came about by accident, the treatment might well be a stem cell transplant, which, happily, is on our agenda. (The first stem cell transplant [via bone marrow] was performed after a radiation accident in the early days of the nuclear business).

In addition to various drugs that counteract some of the unpleasant and dangerous side effects of the poisons, immunosuppressants Cyclosporine and Mycophenolic acid join Immunoglobulin to pave the way for the new stem cells expected on Wednesday.

Posted in [Uncategorized](#) | [5 Comments »](#)

**April 10, 2007**

[Day -1](#)

Since tomorrow is the transplant day (Day Zero), the call today Day -1! Last night, we officially entered the really difficult stage. Aaron is feeling the effects of the chemo and radiation. He's vomiting everything. He has mucositis—mouth sores—because of the high dose chemo. Thankfully, he can still swallow which means he can take his medications. Praise God! Aaron is very weakened and in a lot of pain. Someone right across the hall died last night which adds to how hard this is! Please, keep that family in prayer, too.

The doctors advise that we shouldn't have any visitors so that we limit the amount of germs we come in contact with. Any little germ could be life-threatening to Aaron and we don't want that! We'd rather be extra cautious. We'll let you know when visitors are OK again. Thank God for technology because, even though we can't have visits right now, we can keep in contact with emails, calls and comments that you post on the blog. Thank you, thank you, thank you for your prayers. And thank you very much for letting us know that you are praying. We love you all!

So let us come boldly to the throne of our gracious God. There we will receive his mercy, and we will find grace to help us when we need it most. Hebrews 4:16

[10 Comments »](#)

## Chapter 4 • The Final Battle • April 11, 2007 – June 20, 2007

### *Transplant*

**April 11, 2007**

[Wednesday, 11 April 2007 \(AKA, day 0\)](#)

Waiting around for the stem cells is a little spooky. The radiation and the poisons have accomplished their task...they have permanently destroyed Aaron's immune system: his wellspring of life, the fount of his blood, is a withered wasteland. Without new stem cells, Aaron, looking and feeling much better than he has on many previous occasions, will certainly die. In all the world, there is but a single small plastic pouch whose contents can offer him life. There is no backup, no fallback option, no second bag waiting in the wings should the first one fail.

Finally, a little before 2 p.m., word arrives that the transplant is scheduled for 2:30. Aaron is given steroids and antihistamines to prepare.

Around 3, Dr. Jay opens the birthday-party postered, ballon decorated door of room 1034 and enters with a red-and-white, 6-pack sized hard-side igloo cooler with pivot top and incongruous orange "BIOHAZARD" label. From the Biohazard 6-pack he extracts a half-pint sized pouch which looks for all the world like a shrunken unit of blood. We don our party hats as day nurse Rick connects this most unassuming pouch to the Groshong catheter in Aaron's jugular vein, opens the catheter valve, and assists the vital flow into Aaron's veins with a hypodermic also connected in line. 20 minutes later, the pouch is empty. The stem cells are flowing toward their new home.

The Blessing of the Cells

Be fruitful, and multiply, and replenish the marrow.

Restore that which is laid waste, and

Reclaim that which the enemy has usurped.

Bless, oh God, creator of all and giver of life, the many sacrifices and great efforts that have made this day possible. For these sacrifices and for these efforts we are filled with gratitude.

Surely goodness and mercy shall follow us all the days of our life, and we will dwell in the house of the Lord forever.

[8 Comments »](#)

**April 13, 2007**

[Day +2](#)

Aaron's white count dropped to zero today. He has really bad mucositis—so, bad he can't eat and it hurts too much to talk. We're looking for a store to buy a Magic Bullet at as I write this. The chemo is starting to kill off all of the cells in the lining of his digestive tract. From what we've heard, it is a normal and inevitable side effect. As soon as his white count returns, the mucositis should go away. By the way, the weird audio seiures have stopped. Praise God! Aaron is still more sensitive to sounds than usual, though. Not much else to report—thank God for quiet, boring days!

Thank you for continuing to pray for us!

Psalm 71:1-5 O Lord, I have come to you for protection; don't let me be disgraced. Save me and rescue me, for you do what is right. Turn your ear to listen to me, and set me free. Be my rock of

safety where I can always hide. Give the order to save me, for you are my rock and my fortress...O Lord, you alone are my hope.

[8 Comments »](#)

**April 16, 2007**

[Day +5](#)

Aaron is so awesome! I can't believe how much he puts up with. I'm immensely proud of him! He continues to be in a lot of pain from the mucositis. Last night, he threw up which could not have made his throat feel any better. His white blood count is completely zero. A couple of days ago, he got a unit of red blood and a unit of platelets. The platelets were from a directed donor! Thank you, thank you to all of you who donate platelets. He ended up getting a fever that day, probably from the red blood unit he received—we notice that he has a reaction everytime he receives a unit of red blood. For instance, Aaron got a unit of red blood today. Around 2 o'clock, which was a little while after the blood had finished being infused, he started having trouble breathing and was wheezing. We called for the doctor to come in. They put him on oxygen for a couple hours, took an EKG and a chest X-ray. By 4 o'clock, he was a lot better. We think that he had a reaction to the red blood cells. Next time, we are going to see if they will give him benadryl ahead of time to help prevent this type of a thing. We also found out today that two tests they did on Aaron came back positive for the bacteria c-diff. There are a lot worse things he could have—praise God that this is something they can give him medicine for!

Because of our experience with Aaron being in ICU for respiratory failure, one of the things I have a hard time not getting scared about is breathing trouble. As soon as I see his O2 saturation go below 90, I always start to panic. We put Bible verses up all over Aaron's room—it is quite colorful. We get a lot of comments! One of the reasons I have the verses on the wall is for times like today. As soon as I moved past being concerned about Aaron's breathing to being afraid, I went around the room "praying" the verses. Thank God for His word! I am so thankful that He has given us what we need for times of trouble in the Bible. I glorify God for hearing my cries and responding with mercy and faithfulness. You just have to read Psalm 91—that is what I prayed and that is what I received! Thank you, God!

Psalm 91: Those who live in the shelter of the Most High will find rest in the shadow of the Almighty. This I declare about the Lord: He alone is my refuge, my place of safety; He is my God, and I trust him. For he will rescue you from every trap and protect you from deadly disease. He will cover you with his feathers. He will shelter you with his wings. His faithful promises are your armor and protection. Do not be afraid of the terrors of the night, nor the arrow that flies in the day. Do not dread the disease that stalks in darkness, nor the disaster that strikes at midday. Though a thousand fall at your side, though ten thousand are dying around you, these evils will not touch you. For he will order his angels to protect you wherever you go. The Lord says, "I will rescue those who love me. I will protect those who trust in my name.

When they call on me, I will answer; I will be with them in trouble. I will rescue and honor them. I will reward them with a long life and give them my salvation."

[9 Comments »](#)

**April 20, 2007**

[Day + 9 \(by aaron\)](#)

I am feeling pretty crummy today and have had an almost-fever (just .1 degree less than an official fever) for two days now. I have been feeling really cold, very achy, run down, and super tired.

My mouth and throat feel quite a bit better, though! Today I have taken sips of juice where I actually take more than one gulp at a time compared to taking a long time with the juice sitting in my mouth trying to get the swallow to happen. Needless to say, pills have been very hard and painful to take. But it's getting better!

Overall, we are continuing to enjoy the theme of, "it could be a lot worse."

Natalie and I had the most incredibly wonderful experience yesterday!!! God blessed us in an amazing way. Unfortunately, that is all I am going to share with you! Sorry. :-) I just wanted you all to be able to rejoice and Praise Him with us for what he did and revealed to us.

I love you all, thank you so much, and God bless you ever so richly!

[4 Comments »](#)

**April 22, 2007**

[Day +11](#)

Aaron has been bouncing between having an "official fever" and just on the verge of it for a few days now. The mucositis in his mouth is much better but it is much worse in the esophagus. Thankfully, he has been able to drink Ensure and blended soups and has not been put on TPN (IV nutrition). He has been vomity, weak and just plain yucky lately. He hardly talks but has been up to playing World of Warcraft a little bit today. He has been receiving a lot of blood products. Yesterday, it was 2 red bloods and a platelet. Today, it has been 1 platelet. Thank you to all who drive down to donate—he has been receiving his directed donors this time!

We've asked God to let this go better than expected and I always am amazed when I consider how He has done just that so far. When we talk to other family members of those who have had stem cell transplants (there are at least 5 families on the floor), we hear how hard of a time these other patients are having. Today, a lady told me of her husband who had a transplant the day after Aaron. He has had kidney, liver, and lung trouble. He swallowed his tongue yesterday, whatever that means. Please, remember these other patients/family members that we are meeting when you pray. We do our best to point them to Christ!

We miss you and love hearing from you. We are going to try to update the blog daily from now on—sometimes there isn't a lot new though since we are just waiting for engraftment. Thank you for your fervent prayers!

My eyes are always on the LORD. Psalm 25:15

[4 Comments »](#)

**April 23, 2007**

[DAY 12 \(by Aaron's mom\)](#)

If Ken, Natalie, or Aaron is too tired, too busy, or too stressed to blog, it becomes my turn. This is Aaron's new Blog Rule. Of course, this means you read what I think is happening, not necessarily what's actually happening. Plus, I never report anything I can't spell ( :

Aaron continues with a mild fever and chills. His docs suspect a small infection, maybe in the lungs. Aaron is still at zero white blood cells so all infections, minor or major, are a concern. It could even be his body's reaction to his antibiotics, which is really weird. He feels generally bad, but not acutely in pain anywhere in particular. Doctor Paquette is happy with his progress.

A few of you have asked the significance of 100 days. This is part of the Transplant Protocol: Aaron must stay first in the hospital, then near the hospital for the hundred days following his stem cell transplant. That's the plan, so here we are. God bless you, and thanks for your steadfast prayers.

[2 Comments »](#)

**April 24, 2007**

[Day +13](#)

Today was a little better day than yesterday. After several days of having a fever, the source has not been discovered. That means the blood cultures have had enough time to grow any bacteria, fungus, etc. that may be causing an infection. All cultures have come back negative. The CT scan of his lungs also showed no sign of infection—Praise God! Because of all the vomiting, pain and fever that he has endured the last few days, Aaron is pretty weakened. He has not held down any juice or ensure for the last few days so, they started him on IV nutrition tonight. Hopefully, this will help strengthen him. He received platelets this morning and is receiving red blood tonight.

Today was really neat because we saw 2 of our ICU heroes! This morning, we got to see Dr. Gina Lee who was Aaron's doctor when he was first admitted to the ICU. She was always honest, helpful, thoughtful and brilliant in caring for Aaron. We are so blessed to have had so many wonderful doctors! Dr. Lee reminded me of how the attending physician did not hold much hope in Aaron's survival back in June. She called Aaron a miracle patient. I'm so glad she recognizes the mighty miracle that God has done on our behalf already. Maybe you will remember, back in June that Aaron had a tremendous experience with coughing incessantly for 4 hours (<http://aaronboydston.com/2006/06/09/its-praise-god-time-again/>). God sent a respiratory therapist, Mihai, to stop the exhausting ordeal. Today, Mihai brought Aaron a breathing treatment that helped Aaron have a little less difficulty with breathing. It was tremendous seeing 2 huge figures from Aaron's ICU days that we have not seen in several months. Through their presence here today, we have been reminded of what God has done already for us and we are excited about what we have yet to see Him do! Much love to you all!

Who can list the glorious miracles of the Lord? Who can ever praise Him enough? Psalm 106:2

**April 25, 2007**

[Day 14 \(Aaron's mom\)](#)

After comparing chest scans from the past week, the a.m. doctor announced that Aaron's lung infection was greatly improved, which was surprising because we didn't know he had a lung infection until that moment. I think they suspected an infection but couldn't confirm it until they saw the last scan and how much clearer the lungs looked. So praise God, He healed the lungs before I had time to work up a good worry!

Also, the rash Aaron has is not typical of the classic Graft vs. Host Disease, so that is good news. And, he has been swallowing with less pain which makes taking his 15-20 pills a day easier.

We have settled into a routine and a general calmness prevails; I credit your prayers. God Bless You!

[2 Comments »](#)

**April 26, 2007**

[Day +15](#)

Early this morning (1 a.m. Thursday), Aaron got a severe, crushing headache that concerned the doctor enough that she sent us to the basement for an ultrasound of his head. We got back into the

room at 2 a.m. and after waiting up for 2 hours for the results, we finally went to sleep without hearing anything. We did hear later, that the ultrasound was fine. Praise God! Praise God! Praise God! They also did a couple of extra tests that show Aaron isn't having graft versus host disease. Praise God, again! The rest of Aaron's day was quiet. He received platelets. No fevers but still occasionally vomiting. He reports feeling worn and he looks that way too. That God wants us to call on Him and rely on Him for everything we need (even semi-incoherently in the middle of the night) is amazing to me. I am so glad He never tires of hearing me call on Him because I realize my profound daily need for Him.

Who is like the LORD our God? Psalm 113:5

[1 Comment »](#)

## ***Engraftment Begins***

**April 27, 2007**

[Day +16: First Sign of Engraftment](#)

What we have prayed for has happened. ENGRAFTMENT HAS BEGUN. The doctors came in this morning announcing that Aaron has 100 neutrophils. That means he is starting to make his own white blood cells using the new stem cells he received. Please, continue to pray that the engraftment is completed without complications, such as graft versus host disease. GVHD can be mild to severe and can first appear within hours of transplant to several months later. Please, pray that any GVHD that Aaron experiences will not be significant. Let's praise God a super bunch!

Then God said, "I am El-Shaddai—'God Almighty.'" Genesis 35:11

[12 Comments »](#)

**April 29, 2007**

[DAY 18 \(Aaron's mom\)](#)

This weekend was nicely uneventful. Aaron continues to receive blood products (thank-you, donors!) His coloring looks better to me, and he has been walking up and down the hall at least once a day. His sister, Annalyse, stayed over night for the first time and had beginner's luck: It was a vomit-free night!

We continue to encourage those first stem cells, "Make yourself at Home!"

[3 Comments »](#)

**April 30, 2007**

[Day 19 \(Aaron's mom\)](#)

Today's blood test revealed that Aaron's new stem cells are continuing to make more white blood cells. Baby steps on the cellular level! Cord stem cells are usually slower to engraft than adult stem cells because of the smaller quantity used, but our blessed batch is about five days ahead of schedule. Oh, yes! So far, Aaron is being a very good host, but does feel like his body is working overtime. He is very exhausted, bone tired, but he could have an immune system in another week or so. Praise God!

[5 Comments »](#)

**May 1, 2007**

[Day 20 \(Aaron's mom\)](#)

Aaron's spirits are a bit low today. Though the transplant is going well, I suppose it's hard to stay in the "big picture", where everyone is telling you that everything's going perfect, while you live the small picture, feeling perfectly awful every minute.

Meanwhile, back to the big picture: The stem cells continue to hold their ground. Praise God.

[2 Comments »](#)

**May 3, 2007**

[Day +22](#)

Quick Update: Aaron is exhausted. It is an exhaustion from all the cell rebuilding that is going on, not from a lack of sleep. He has been miserable and extra untalkative but today he reports feeling a bit better. Praise God! His rash, skin and bruises are improving. He is taking a short walk once a day. He continues to be on IV nutrition because he only consumes juice by mouth (oh, and like 30 pills a day!). Because it is the beginning of a new month, we have all new doctors. God really planned for excellent physicians to be on service during the crucial month of April. I know that it wasn't a coincidence that Aaron's primary oncologist was the attending physician last month. We are so grateful for the wisdom that God gives all of the medical staff. Please, pray that Aaron will be well taken care of by these new doctors and there will not be any confusion or problems caused by the change in physicians. His neutrophils (baby white blood cells) are climbing—they are at 400 today, the highest they have been! God is awesome! When the neutrophils reach 500, that's when the doctors want to discharge. Today, during rounds, the doctors said they were very close to discharging from their standpoint. The only thing that will keep Aaron in the hospital once the neutrophils reach 500 is being on the IV nutrition. So, please pray that he will be able to eat soon! Once Aaron is discharged, we will go across the street to the Tiverton. Thank you for your love and prayers!

Be joyful in hope, patient in affliction, faithful in prayer. Romans 12:12

[No Comments »](#)

***Engraftment is Officially Done***

**May 5, 2007**

[Day +24](#)

Yesterday, Aaron's new stem cells officially engrafted. He is not in the process of engrafting anymore, he has engrafted. Amazing! Praise God for this awesome news. One of the most dangerous parts of doing the stem cell transplant is having Aaron's body reject the new stem cells. Before starting the procedure, the biggest concern was "what if Aaron doesn't engraft?" because there was no backup plan. There weren't any other cells to try. Praise God for faithfully protecting and caring for Aaron.

Discharge from the hospital, this time, is quite a process. Usually, the first time the doctors mention discharge, you are out of the hospital in less than 12 hours. However, because of the complicated medication schedule and his need for eating before leaving, it is taking some time to get discharged over to the Tiverton. I met the discharge nurse yesterday and actually had to have a meeting about how to care for Aaron when he gets out of the hospital. She explained that getting out of the hospital and getting through the next few months is just as difficult of a hurdle to get over as what we have just done. She said with the various doctors appointments, medication schedule and meals, you have a



pretty full day everyday. The only other thing to report is that Aaron's temperature is running as high as it can without being considered a fever (100.2). Please, pray that his temperature will return to normal and that it won't be anything that keeps him in the hospital longer. :) Thank you so much for continuing to check in on us and for keeping us in your prayers!

"Therefore, know that the LORD your God, He is God, the faithful God who keeps covenant and mercy for a thousand generations with those who love Him and keep His commandments."  
Deuteronomy 7:9

[4 Comments »](#)

## ***Mysterious Fevers***

**May 8, 2007**

[Day 27 \(Aaron's mom\)](#)

The docs have been very puzzled about Aaron's high fevers. They've been running tests since Saturday, and all the cultures have come back negative. They even removed his surgically implanted I.V., which was allowing Aaron fewer pokes each day, in case, it was the site of infection.

This morning, as Dr. Paquette pondered these fevers, sweet Natalie, the family Med-Sleuth, asked, "In the blood report, I noticed the phrase 'Toxic Granulation seen' under the neutrophil count. What does that mean?"

Suddenly Dr. Paquette perked up. "Ah ha! Maybe I do know what's going on!"

So here is today's theory, inspired by Natalie's find: Aaron's new go-getter white blood cells are attacking one of Aaron's daily drugs (Neupogen: a drug that mimics a virus in order to simulate more white blood cells, or something like that.) The fever could be the by-product of that battle. This is a very hot theory; all the docs are now looking around, asking, "How come the neupogen wasn't stopped earlier??"

If this theory is correct, Aaron's fevers will drop as his blood levels of that drug drop. I hope so; then we can go across the street.

OF INTEREST: Know anyone pregnant? Encourage them to donate their umbilical cord. It is free, no risk to mom or baby, and can save a life. If there's a history of cancer (or other diseases) among siblings, storage in a cord bank might be recommended by their family doctor. Here's a sample of pricing: 1yr.=\$1,420, 5yrs.=\$1,860, 10yrs.=\$2320. (And, no, we don't get a commission.)

Keep praying! Love, the Boydstons

[7 Comments »](#)

**May 9, 2007**

[Day 28 by Aaron's mom](#)

Though the mystery fevers have continued much to our dismay, Natalie's Clue (the neupogen theory) still holds water, but the docs want to cover all their bases so now we have entered the Scan Wars. The Team (this month's rotating herd of doctors that visit each morning) and Doctor Paquette, his oncologist, both want scans done on Aaron to look for a possible hidden source of infection, but disagree on the type of scan. Tomorrow we'll see who wins (I'm betting on Paquette)

HOT OFF THE PRESS: The nurse just now took Aaron's temperature: NO FEVER!

First time in four days! Maybe we're getting there!!!

By the way, remember that rash? It's still there and actually worse, so opinion is leaning towards, "Looks like Host vs. Graft...plus some petechiae." (Broken capillaries from low palette count). The rash is really awful looking, but doesn't bother Aaron too much. They may give him some steroids to beat them back. Pray this remains a mere scuffle between Aaron the Host and his guest Graft.

Praise God there hasn't been any panic-level issues! (Remember Jan./Feb.!!!)

Of interest: Aaron's sister, Rose, achieved her Black Belt in Kung Fu San Soo (Karate street fighting) this week-end, so as Aaron recovers in his weakened state, he has a killer body guard!

[4 Comments »](#)

## ***Blood Draws Become VERY Painful***

**May 10, 2007**

[DAY 29 By Aaron's mom](#)

The Fever Mystery continues. Yesterday evening when I reported, finally, a lack of fever, I wasn't aware that Aaron had already received his first dose of steroids for his rash. Since steroids can mask a fever, we still don't know whether we're dealing with an infection or the Neupogen Effect ( or, as I call it, Natalie's Clue.) Goodness!

Remember the Scan Wars? The Team almost scored one over Doctor Paquette. This is what happened: The Team got their way and Aaron was wheeled downstairs where a tech started drawing blood. The Team intended to take that blood, filter out some stems cells, mark them in some scan-friendly manner, put them back in Aaron, and watch if they hightailed to some hidden source of infection. But none of that happened. Trying to draw the necessary blood proved too painful for Aaron. See Aaron's OUCH blog. Concerning another attempt at this Stem Cell Scan: Doctor Paquette said, "Just say 'No!'"

As always, I appreciate your prayers, Love, and an occasional chocolate.

[1 Comment »](#)

[Ouch \(by aaron\)](#)

I was brought down to nuclear medicine, just a bit ago, for what we thought was one of the scans. Things were all mixed up and as it turned out, I was just going down to get a big load of blood drawn, in preparation for a scan. Well, the technician went to poke me, and I even engrossed myself in an R/C car magazine (one of my favorite hobbies) to take my mind away, but, "YEEEEEOHHHHH!!!" The pain was excruciating. It was all I could to muffle my cries of pain, my magazine dropping, my eyes closing, my mind going blank, just circling in darkness, as he probed that needle around trying to get into a vein good. He did not. Not a good connection, anyway, and still very, very, very painful. So he pulled the needle out. It was just like the initial pain, only with the promise of being short and ending with relief. Sweet relief. For quite some time, I just lay there, crying, my mind spinning and trying to get control of my breathing. I was unable to let him try again, though he really wanted to.

But praise God! This is the first time, this entire hospital stay, I have had to go through anything so painful. God bless you all, so much.

[7 Comments »](#)

**May 11, 2007**

[Day 30 By Aaon's mom](#)

Today was quiet. The steroids for Aaron's rash have one nice side effect, he feels a little perkier. It will take two days for the steroids to wear off, so they could be masking a fever meanwhile, and hiding an infection. If Aaron's temperature is normal Sunday, we get to go across the street.

Pray that happens. Doctor Paquette said, "You have to get out here before you catch something!"

Yesterday, a certain doctor, henceforth called Dr.W, came to check on Aaron. This fellow has been around, off and on, since last May. What makes him especially memorable is that his five minute visits, even after insurance, have been costing Aaron \$350 out of pocket. He's a pleasant fellow, but not that charming. Finally, Thursday morning, when Aaron caught sight of Dr.W entering his room, he said, "I'm fine! I'm fine! Don't worry about me!"

This was a bit off putting for Dr.W. He asked, "What's wrong?"

"I can't afford you!" answered Aaron.

After a short discussion, Dr. W assured Aaron that those previous billings were a mistake and he would look into it. So, there's a good chance of a refund. Plus, Aaron had him sign something scribbled to that effect.

A hospital is no place to be shy\_\_in lots of ways!

[1 Comment »](#)

**May 12, 2007**

[DAY 31 By Aaron's mom](#)

Super Med-Sleuth Natalie was looking over Aaron's blood lab reports and noted his blood sugar was very high (a by-product of steroids). After a few hours and no order of insulin materialized, she asked for another a glucose test. A second test measured a really high glucose Level (401mg/dl)! Insulin was given, and over the next several hours Aaron's blood levels returned to normal. The Team is not happy with a certain intern in charge of reading Aaron's lab reports. Maybe, Natalie should start billing for her services (at Dr.W's rate!)

LESSON: When you're in the hospital, bring at least one really smart relative with you.(Or you could hire Natalie at the family rate? Ken costs extra.)

After some discussion, the Team thinks it best Aaron stay a few more days so they can wean him off steroids slowly. By midweek he will be clear of them and we can finally see if the fevers are gone.

Prayer for attentive Doctors! (Doctor Paquette can't be here all the time!)

And thank God for Aaron's increasing immune system!

[6 Comments »](#)

**May 14, 2007**

[Day 33 By Aaron's mom](#)

One lone fever at 4:00 AM has us concerned, but Aaron has been free of fevers since then. He tested positive for that C.Diff organism again so it's back to gown, gloves, and masks for staff and visitors. Plus he's back on the C.Diff specific-antibiotic, which I think is responsible for his nausea and vomiting returning today (at least one nurse agrees with me!)

The Team mentioned their desire for a head scan this morning to check for infection because Aaron sounded a bit congested, but nothing happened. Maybe the fever free afternoon has put that idea on hold.

As to when Aaron can go across the street; I heard anywhere from two days to two weeks. Makes it hard to plan your social calendar...

Pray that Aaron starts to eat more. He is thankful for the ability to swallow again without actually thinking about it, but has no appetite.

Hope everyone had a nice Mother's Day.

[2 Comments »](#)

## **May 15, 2007**

[Day +34 \(by Natalie\)](#)

Aaron hasn't had a fever since yesterday morning. Praise God! They determined he has C.diff and are treating him accordingly. We were surprised to learn, this morning, that Aaron is neutropenic again. If you remember, they determine you have engrafted by when you are not neutropenic anymore. Aaron officially engrafted on Day +24. He should not have fallen back into neutropenic ranges. The doctors said this morning that there are a few medicines Aaron is taking that could potentially be the cause. We asked the attending physician how weird this was. She replied that she is not happy about it but she did not seem overly concerned. They will eliminate a drug that he takes every Saturday (Bactrim) to see if that helps and will also restart neupogen. We haven't heard anyone say anything about what this means in terms of engraftment yet. Today's date is May 15th. It was May 17th of last year that Aaron was diagnosed with AML.

Just as you cannot understand the path of the wind or the mystery of a tiny baby growing in its mother's womb, so you cannot understand the activity of God, who does all things. Ecclesiastes 11:5

Personally, I try not to ask God for anything that I think is me trying to tell Him how to do His job (i.e., make Aaron's white cells increase, make his rash go away, let him come home now). I know that I don't have the foggiest idea how God is working everything out for Aaron's complete healing. There are so many complicated and intricate steps, reactions and timings that only God can control to bring about Aaron's restored health. I've seen "bad" things turn out to be "good" things and "good" things turn out to be "not as good" as I thought. But, in everything, I have seen God's protective and powerful hand. The invisible qualities of God that are evident in creation are also evident in everything we have gone through in the last year. God's eternal power and divine nature have been on display through Aaron's sickness so that we are left without excuse for not knowing God better. I have learned a tremendous amount about God in this last year and I hope you have, too! So, as we are all feeling a little nervous down here with this morning's changes, we invite you to rely on God with us for a spectacular resolution to this "problem." Just as we have trusted Him, relied on Him and petitioned Him for the last year regarding Aaron, lets continue to do so expecting to see Him do great things and praising Him for what He has done already. We love you!

[3 Comments »](#)

[How I Feel \(by aaron\)](#)

Tuesday, May 15th, 2007

Blessed beyond measure.

[3 Comments »](#)

## **May 16, 2007**

[Day 35 by Aaron's mom](#)

Good news! We were shocked and amazed this morning to hear that Aaron's white blood cells made a mega-leap from a pitiful 1,300 count to a hefty 10,900 count (normal is between 3,000-9,000 count).

My first thought was They really prayed! And God answered!

My second thought was Is this okay? Does Aaron have a big infection, causing a sudden rise in the white blood cells?

My third thought was Wow! What a great Immune System if he does have an infection!

And finally Thank you, thank you, Lord!

Happy to report Aaron is feeling well, with no signs of infection. The docs are all smiles and ready to boot Aaron out. We may be going across the street tomorrow!

[8 Comments »](#)

## ***Out of the Hospital***

**May 17, 2007**

[May 17th, Happy Anniversary! \(by Natalie\)](#)

One year ago, God chose us to serve Him in a new way. Aaron was diagnosed with leukemia and we were whisked away from our home to UCLA. God sent us to this different world, this mission field.

Today, we celebrate the goodness of the God we serve. Through this last year, God has demonstrated that He is Almighty, Healer, compassionate, Defender, always near, Creator, incomparable, Provider, Love, joy, life, our Shepherd, Truth, perfect, omniscient, unchangeable and unquestionably faithful. He is unequaled. Let's Give glory to God for all the marvelous works that we have seen Him do through and for us! We especially thank God for the incredible love and support that we have received from all of you. For us, it truly has been a manifestation of Jesus' peace that is beyond understanding. We could not have made it without you.

The decorations are down. The room has been cleaned out. Transport has been called. We have been discharged. We are on our way over to the Tiverton!

PRAISE GOD!

In His grace and with so much love,  
Aaron and Natalie

"You will know that I AM the LORD; those who put their hope in Me will not be put to shame." Isaiah 49:23

[12 Comments »](#)

**May 19, 2007**

[Close Calls \(by aaron\)](#)

I got to the Tiverton (hotel right next to the hospital) Thursday evening; oh what a joy it is to be with my wife and kids again!!! I got to surprise my kids, though Michaela said she suspected I was getting out of the hospital. I can not even begin to express how great it is to be with them again. My heart has been exploding with joy!

Unfortunately, I woke up yesterday with a mild fever. Fevers are a very quick ticket right back into the hospital. Thankfully, though, it was mild enough that the doctor was not too worried, so he instructed me to just keep an eye on it. We were very happy for this, because the last thing we want to do is bounce in and out of the hospital. Thankfully, I have not had a fever today! But I have also had a few

small blisters form around my waist that could be another ticket back into the hospital. Sheesh! We just need to remember that these “minor complications” are completely expected. In fact, most of the literature describing what to expect after a transplant says to plan on going back into the hospital at least once. That does not mean we have to, though!

I am not sure what the plan is from this point because the “plan” can vary so much and I am little clueless anyway. We will have to stay down here, right next to the hospital for at least a few weeks because I am still under such intensive care and my health status can change in a flash for many, many reasons. So the next several weeks just have to be taken day by day, week by week, but every day that passes is another day conquered and, right now, I definitely feel a wee bit stronger each day!

Praise His name and may He bless you all ever so richly in His marvelous grace!

[2 Comments »](#)

**May 20, 2007**

[The Kids Had Something to Say](#)

I like today because Daddy is home. It is awesome because I can see his face. I was sad when Daddy was in the hospital. I didn't like it because I never got to see him. I was so happy when he came home that I was jumping up and down. Everybody knows that Daddy is the best daddy in the world. I get to play with him and talk to him and show him things. We watched Night at the Museum with him. God is so great because He made Daddy better and He brought Daddy home. There's only one God and the only God made Daddy better. Everyday, God heals somebody. I'm glad Daddy is home so now I don't have to miss him everyday!—Michaela

I love Daddy so much. I play with him with my toys. I want to play bowling ball on his Wii. I missed him so much. I can't miss him so much anymore 'cuz he's not at the hospital anymore. I'm going to shave my head so I look like Daddy. And when he was in the hospital, I missed him so much. And I give him a tissue. And I love him.—Christopher

[7 Comments »](#)

**May 24, 2007**

[Day +43 \(by Aaron's mom\)](#)

Dear Family and Friends,

Sorry communications have been scarce for several days. My lap top has been out of commission for the past week (Ken is working on it), and Natalie's new role as home-nurse is very time consuming. Plus Aaron's new mix of drugs have kept him too drowsy to blog.

Aaron's blood levels continue to hold. He has not needed blood products since his release. Praise God! The readings tend to be just on the lower edge of normal so everything is moving in the right direction.

Monday's appointment was very exciting. There were about seven doctors plus nurses all conversing about Aaron. This is his new out-of-hospital team headed by Doctor Paquette, plus his new study team. Aaron has agreed to be part of test group trying a new antiviral drug that's easier on new stem cells. The study is being led by Doctor Winston (Remember him?) They all wanted to see a new rash on Aaron's back. A spirited argument ensued. Aaron said it was like a Boydston/Burke dinner. The Shingles contingency won. To our relief, Aaron's shingles aren't causing the pain normally associated with that dreaded disease thanks to early detection and a miracle drug. Can anyone tell me why the

Zoster virus (dormant Chicken Pox virus) is called Shingles? Is it because the scab falls off like a shingle off the roof?

Natalie has been keeping Aaron's 40 pills on track, flushing his lines, taking his temperature, and even giving I.V. meds. I'm sooo glad Natalie is detail oriented. I wonder how other families cope with the transplant regiment. We're all hoping Aaron won't have to stay the full 100 days here at UCLA. The Tiverton House is very lovely but not Ojai. We continue to thank God for an uneventful transplant as we hear the horror stories of other recent transplants.

[4 Comments »](#)

**May 27, 2007**

[Day +46 \(by Natalie\)](#)

Aaron is doing pretty well. He has had no fevers since receiving medication for his shingles. The shingles seem to be responding well to the medication. He is starting to grow a little bit of hair. He has babysat the kids a few times while I run to the store. We went on a longish walk yesterday. He has to be careful not to be in direct sunlight because that can activate graft versus host disease. He has been shaky and jittery for some reason lately. He is a little frustrated because he is trying to get some work done and can't stay awake long enough to finish his task. We had an exciting morning today. We were awakened to the sound of the fire alarm. Christopher was excited to see the four firetrucks come with firefighters in full gear. They even sent their ladder up to the second floor. Everything was OK. It was only smoke from someone cooking—Praise God! Mostly, we are just enjoying family time together. After over a month of being separated, it is nice just to be in the same room together. Aaron will have a blood draw tomorrow (Monday) and a doctor's appointment on Wednesday. We appreciate your prayers immensely. God is awesome!

May the Lord lead your hearts into a full understanding and expression of the love of God and the patient endurance that comes from Christ. 2 Thessalonians 3:5

[3 Comments »](#)

**May 30, 2007**

[Day 49 By Aaron's mom](#)

Nothing new to report, which is good. Aaron is well enough and out of pain enough to be frustrated by his constant exhaustion. He wants to organize his medical paperwork, but keeps falling asleep. Blue Cross isn't known for their dramatic content.

At today's appointment, Dr. Paquette said Aaron's blood counts are still low, but he's happy with his progress. Nevertheless, that means neutropenic precautions continue in full force. If you feel healthy and would like to visit, call ahead and we'll let you know if he has an immune system that day (it goes up and down!)

Henry Blackaby: "God has always given His people assignments that are too big for them to handle alone, so that a watching world can see—not what we can do—but what God can do."

[3 Comments »](#)

## ***Back in the Hospital***

**June 1, 2007**

[Day 51 Aaron back in Hospital](#)

Last night Aaron was admitted back into UCLA. Tests show some kind of partial bowel obstruction. We'll let you know more when we know more. Please pray. Aaron's mom

[3 Comments »](#)

**June 2, 2007**

[Day +52 \(by Natalie\)](#)

Just a quick update. Aaron is still in the hospital. After further testing, it seems that Aaron has an infection (colitis) and not a bowel obstruction. They are trying some antibiotics to see if that helps. In addition to the bowel problem, the other big reason why I took Aaron to the doctor (who sent him to the ER) was because he was weak and could not stay awake. It seems that the pain medicine that Aaron was sent home on caused a lot of problems as it built up in his body. One of those problems was a lowered sodium level in the blood. That's probably why he was becoming drowsy and unresponsive. After looking over the blood reports from the last week and thinking about how Aaron has been doing, we see that as Aaron's sodium level dropped, he became less able to stay awake. If that goes on too long, it can lead to a coma which is exactly what I believe God was protecting him from. Ever since he was given IV fluids and had his pain medication switched, Aaron has been much more alert. Praise God! Aaron looks A LOT better than when he was admitted and we are hoping that he won't be hospitalized for much longer. We appreciate your prayers for a healing from this infection, wisdom for the doctors and God's perfect control of all the intricate levels that must be maintained to keep his body functioning correctly!

God's way is perfect. All the Lord's promises prove true. He is a shield for all who look to him for protection. 2 Samuel 22:31

[5 Comments »](#)

### ***The Real Last Discharge***

**June 4, 2007**

[Day +54: Back at the Tiverton \(by Natalie\)](#)

After spending a few days in the hospital, Aaron improved a good deal. However, last night (Sunday night), Aaron started getting nauseous, vomity, drowsy and weak again. We don't know why this happened all of the sudden. His sodium levels are OK. He is so nauseous that the nausea medication doesn't work. He can't eat or drink. Despite the change overnight, the team of doctors at the hospital decided to discharge him today. It is a little frustrating leaving with Aaron in much the same condition as when he went in. I guess colitis is not a good enough reason to keep him in the hospital. Please, continue to pray for all of us. Aaron is so uncomfortable. Also, it is quite a consuming job trying to figure out how to take care of him, how to get the medicine down him and whether he is doing poorly enough to contact a doctor. We love and appreciate you!

What I have learned the most:

I need Jesus. My need I now confess. No Friend like Him, in times of deep distress. I need Jesus. This need I gladly own. Though some may bear their load alone, yet I need Jesus. Need Him in the sunshine hours. Need Him when the storm clouds low'r. Everyday, along life's way, yes, I need Jesus. (George O. Webster)

[6 Comments »](#)

**June 5, 2007**



[Day 55 Bad Night by Aaron's mom](#)

Last night was very, very difficult for Aaron. All-over, deep bone pain. The discharge doctor wasn't familiar with Aaron and gave him 8 times less pain medication than normal, which Natalie couldn't get corrected until this morning. Watching a loved one in pain is one of the most helpless feelings I've ever experienced. If that doesn't drive one to prayer... As soon as Doctor Paquette heard, he was appalled and brought the doses up to a reasonable level.

Aaron is doing better today. He actually ate a few bites of food, so thanks for the prayers.

[5 Comments »](#)

**June 7, 2007**

[Day 58 By Aaron's mom](#)

Aaron is still very nauseous, which makes eating difficult, but he is taking a few bits each meal. We just gave him his first multivitamin, which we are praying stays down. His pain level is constant, but managed by his meds most of the time. He has been running a slight fever and his shingles are acting up again. Positive news: His blood labs looked good this morning. His stem cells are working to undo all the damage done by radiation and chemo.

The Home-nurse made an interesting statement to Natalie this morning: "It's your responsibility to catch the nurses' mistakes."

I know there are nurses and care-givers reading this blog. What do you say about the above quote?

That same nurse said some families commit to taking care of a patient before the transplant, and then disappear after the patient comes home. When choosing a transplant candidate, one of the factors considered is: Does the patient have a support group in place? The Home-nurse said he lost one patient because the family flaked out. This may be why he puts so much responsibility on the family. Of course, Pastor Shores always said "Don't accept responsibility where you have no authority." Regardless, Natalie keeps a watchful eye. Praise God.

[10 Comments »](#)

**June 12, 2007**

[Day 62 by Aaron's mom](#)

Aaron's appointment with Dr. Paquette went well. The blood labs look good with counts coming up. Several drugs have been dropped or reduced. Even his pain pills have been reduced a bit (to an amount that would put most of us into a coma.) We're all hoping this will reduce Aaron's nausea and he can start eating. He looks gaunt, but has better color since starting his multivitamin. Vitamins have been discouraged until recently because of possible interaction with some of his drugs. I sure feel better knowing he's getting at least the baseline nutrients. He's only eating about a cup of food a day, but none of his docs want him on IV nutrition. I suppose as long as he is increasing his intake a little each day they're not worried. Getting his digestive system working is part of the program.

The shingles are improving and his low-grade fevers are gone. Praise God!

Aaron has hair! His eyelashes, eyebrows and beard came in first, now his whole head has a five-o'clock-shadow. We were told that the amount of radiation he received could cause permanent baldness but the Burke hairy-gene is prevailing!

Life in a hotel room with three adults, two kids, a hepa filter, medical and home school supplies, an IV stand, wheel chair, art materials, fridge, microwave, toys, a set of bunk cots, and more could be a nightmare, but we're doing fine, grateful for such a great facility.

Thanks for all your prayers as continue on this 100-day march.

[6 Comments »](#)

## ***Tired of Being Nauseous***

**June 14, 2007**

[Day 64 Aaron's mom](#)

Today was just one of those all-around-nauseous days for Aaron that Natalie is "stinking tired of." Most of Aaron's stomach problems are from the very drugs that are protecting him from infection or Graft vs. Host disease. Please pray that Aaron's tummy settles down so he can eat. Today he only had several spoonfuls of cereal and soup, and one single spoonful of ice cream. This is not the Aaron we all know and love!

[5 Comments »](#)

**June 17, 2007**

[Day 66](#)

Continued concerns about Aaron's vomiting and his bowels. Plus, Natalie and Michaela are both feeling under the weather. Lots of minors problems adding up to produce a challenging week-end. Please pray for the whole family. Love to all.

[6 Comments »](#)

**June 18, 2007**

[Day 68 by Aaron's mom](#)

Today Aaron spent a few hours at the hospital clinic with Dr. Paquette. He is sure that Aaron doesn't have a bowel obstruction, which is good news, and believes the nausea is completely from his drugs. He did get IV fluids for a few hours to replace what he lost earlier today from vomiting. We're glad he didn't end up back in the hospital. Across the street is just fine. He's comfortable this evening. I'm hoping he takes a couple bites of his Father's Day mega-cookie baked by Kathy Thomas.

Here's one of several questions emailed to me from Pat Hartmann and my answer.

How do you reconcile the urge to get one million people praying with the "God is in control" mindset?

We are told in scriptures to pray for the sick. Yet, in spite of our prayers, the sick often die unnaturally young. Have our prayers failed? Thousands prayed for Aaron's big sister, yet she succumbed to heart disease during her eleventh year. Was there not a single prayer that met some heavenly standard of faith? I think not. Was her death the by-product of man's free-will: injured in the womb by a man-made toxin? Maybe. Or was it simply God's will she join him in heaven because of some master plan we just don't understand. Very possible. Do any of the above possibilities negate the command to pray for the ill? No! Ultimately, reconciling is a poor substitute for trust. When I don't understand God's will, I trust his character. Healing or no healing, I will not doubt the goodness of my God.

[8 Comments »](#)

**June 21, 2007**

### [Day 71 Aaron's mom](#)

Today was a slow day for Aaron's stem cells; he is officially neutropenic again (no immune system for all practical purposes.) This is not unusual, and the reason he must stay near UCLA for 100 days. Why the sudden drop in white blood cells? Sometimes the powerful antibacterial drugs needed for the transplant will wipe out new white blood cells. It's that old Catch-22. Tomorrow Aaron will get some blood and that should perk him up. He did eat a little today, and it stayed down. Praise God! Continue to pray about his eating. Aaron has lost 50 pounds, weighing in at 127 pounds. He's all skin and bones. Doctor Paquette took him off several drugs and is hoping this will give his tummy a rest.

Thanks for your steadfast love.

Here's another question from Pat Hartmann:

When you are being strong for everybody, who can you be real with?

I have been surprised how many well-meaning Christians make it hard to be "real". There were times when I wanted to share the burden of my fears but felt "hushed" by their belief that thinking and speaking any negative thoughts would demonstrate a lack of faith and "mess up" Aaron's healing. Thank God, I have learned it's not the quality or quantity of my faith, but the object of my faith, Jesus, that matters. I am encouraged that Jesus said, "Your faith has made you well; go in peace" and not "Your perfect, immeasurable, unsinkable, flawless faith has made you well." I'm trusting in my Savior, not in how much faith I can conjure up. Having faith in my faith, feels like another form of "works."

One of the several people I have been able to be real with has been Aaron himself. His God is very Big, and not tripped up by the littleness of my faith. Aaron has never asked "Why me?" but trusted in his Father God, and is honored that God has used his illness to touch lives. A key verse for him as been: "For you have been given not only the privilege of trusting in Christ, but also the privilege of suffering for him." (Phil. 1:29)

[4 Comments »](#)

**June 24, 2007**

### [Day +74 \(by Natalie\)](#)

Taking care of Aaron these days reminds me a lot of taking care of the kids when they were newborns. I am incredibly busy all day long but, at the end of the day, I can't really say what I did except, "I took care of him." It is a constant stress to make sure we get all of the pills down him and (hopefully) in a way that doesn't make him vomit them right back up. We have developed a system which, Praise God!, has been largely successful so far. The secret ingredient has been IV benadryl. Aaron still has his PICC line in his arm so, about 4 times a day, I give him his dose of benadryl through his IV. He is taking the maximum daily dose of benadryl that you are supposed to ever have. This has been a concern to all of us but the doctor says if it is working, do it. Aaron is taking very little food and his pills are for the prevention of rejection and infection. The IV benadryl is the only thing that seems to keep the food and the pills down. Dr. Paquette said he hadn't ever heard of benadryl working like this for someone. Benadryl is so much safer than some of the other anti-nausea drugs. I like to think that God having Aaron's body respond only to benadryl could very well be His way of protecting Aaron from the scary neurological side-effects of the other drugs.

Aaron is really thin. I like to say he's skin, bones and hair because his hair is growing back so much. Dr. Paquette attributes the nausea that is preventing Aaron from eating to the pills he is taking. The doses of almost every drug have been reduced over the last 3 weeks. So far, their reduction has not improved Aaron's nausea at all. Aaron has his weekly checkup tomorrow. Please, please pray for

wisdom. It almost seems to me like they should be looking into other possible problems and not just assuming its the pills.

Biblegateway's verse of the day today is 2 Thessalonians 3:3– But the Lord is faithful, and He will strengthen and protect you from the evil one. I love this verse! It reminds me that God is committed to helping me with the absolute daily physical exhaustion I feel taking care of my sweet husband as well as helping me as I strive to keep my eyes unflinchingly on Him in faith.

[7 Comments »](#)

**June 29, 2007**

[Day +79 \(by Natalie\)](#)

Just a couple of things to keep you caught up!

Aaron had his weekly doctor appointment on Monday. He is still struggling with a lot of nausea which is totally not typical, especially this far away from the transplant. Dr. Paquette lowered the doses on some of Aaron's medication which he has more freedom to do as we get closer to the +100 days milestone. So far, the reduction in medication has not seemed to make any difference with the nausea. So, the doctor talked about doing a scope to check for GVHD, if Aaron doesn't improve soon. Graft-versus-host-disease can attack the stomach and the intestines but Dr. Paquette doesn't think that is what it is because Aaron isn't showing signs of GVHD anywhere else. Aaron lost 5 lbs since last week and he is now 122 pounds. He seems to alternate with good days and bad days. It really is all about the uncontrollable nausea right now. Otherwise, he is doing amazingly well. Everyone is surprised that Aaron hasn't had to have even one transfusion since he left the hospital. That is also unheard of! Praise God for taking such good care of Aaron (and us all)! Please, keep praying for Aaron to be less nauseous. The last few days haven't been too bad but today he's having an awful day with it.

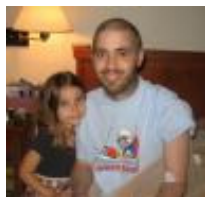
Today is Christopher's 4th birthday, and although I haven't been up to planning a celebration for him, we are overwhelmed with gratefulness that Aaron can just be with us today. Last year, Christopher only got a few minutes on his birthday to spend with his Daddy because Aaron was in the hospital. Christopher got a huge bouquet of balloons from sister this morning, so I think he's feeling pretty special!

I praise Your name for Your unfailing love and faithfulness; for Your promises are backed by all the honor of Your name. As soon as I pray, You answer me; You encourage me by giving me strength. Psalm 138:2, 3

[2 Comments »](#)

**July 2, 2007**

[Day +82 \(by Natalie\)](#)



Aaron had another weekly doctor appointment. We were pleased to be able to report to the doctor that Aaron had a better week with eating overall but especially on Sunday. It seems that reducing the medication last week has started improving his nausea. Also, the reduction in medication last week

seems to have improved Aaron's kidney function. For awhile now, Aaron's kidney has been getting mildly damaged from the medications. This is the first time in a long time that his kidney function has been close to normal. Dr. Paquette responded with glee when he read the labs today. He seemed pleased by all of the numbers. Dr. Paquette called off the scope (that Aaron was going to have done to look for the source of nausea) because Aaron improved some this week. Aaron had some strong pain when the doctor pushed on his abdomen which is about the only thing of concern that arose during the appointment. Again, Dr. Paquette doesn't know what that pain is but he doesn't believe it is graft versus host disease. Aaron lost more weight during the week even though he seems to be doing better—he now weighs 119.6 pounds.

Dr. Paquette is going to be on vacation next week and said that Aaron could skip his weekly appointment next week—he doesn't need to schedule an appointment with another doctor. I've started praying that Dr. Paquette will have a relaxing, safe and blessed vacation. We are so appreciative of his care and consider him to be a blessing from God. God chose just the right doctor for Aaron. We have met all of the other oncologists and Dr. Paquette is the most caring, helpful, encouraging, wise and trustworthy physician of the whole bunch. He gives of his own time without complaining and is always quick to respond to our questions. Praise God for using this man in His healing of my husband! The next time Aaron will go for an appointment, unless he is having some sort of problem, will be on Day +96. That's exciting to think about!

Some of you have asked about the significance of Day +100. It doesn't mean anything concrete really. The first 100 days post-transplant are very critical. There are a lot of rules that have to be followed for the patient's safety, blood counts are all over the place and the need for many medications is high. After day +100, rules are allowed to be relaxed a bit (although we probably won't relax too much—I'm super cautious!), blood counts don't fluctuate so much and medications are reduced a lot.

Thank you so much for your love and support. We are looking forward to when we can be back home in Ojai. Please, pray that God brings that about soon and give Him glory for the marvelous things He has done through Aaron's sickness.

For who can know the Lord's thoughts? Who knows enough to give Him advice? And who has given Him so much that He needs to pay it back? For everything comes from Him and exists by His power and is intended for His glory. All glory to Him forever! Romans 11:34-6

[6 Comments »](#)

**July 10, 2007**

[A New Home! \(by aaron\)](#)

Yet, another prayer is answered, and just in the nick of time. In the next couple of weeks I will be getting to the point where I no longer need intensive and close monitoring by the doctors. This means that it is getting close to go-home time! Back to Ojai. Wow!

You may remember that we moved out of our previous apartment because of mold, which we did not want to risk affecting me negatively when I got out of the hospital. So we have been homeless for quite some time now. Natalie's parents have been very generous, allowing us to live with them in between hospital stays but when we go back into Ojai this time, it will be to our own place! We are very excited! Praise God!

Well, just writing this little bit is pretty wearing for me, so time for me to rest! God bless you all so very, very much.

Chapter 4 • The Final Battle •  
April 11, 2007 – June 20, 2007

[8 Comments »](#)

## ***Home for Good!***

**July 18, 2007**

[Day 98 Aaron is Home!!!!](#)

It's late and everyone is tired so more details will follow, but  
PRAISE GOD, Aaron, Natalie, and kids are back in Ojai!

[7 Comments »](#)

**July 20, 2007**

[day +100!!!](#)



[Here we are in our new home. Home for good and the start of my new life!]

[9 Comments »](#)