

LIVE STRONG DIARY OF DAVID ALLWEISS

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Prologue: One Year Later, December 2006

I wrote this diary starting December 3rd, 2005, three days after my son entered the hospital with cancer. For all of those who have read the diary and been kind enough to share your thoughts or comments with me, thank you. Many of you have said that the diary had a strong emotional impact on you, and has changed your life in a positive way, for that I am thankful. A few have asked questions about specific events, or did not understand some passages, or were curious about decisions that were made.

On this one year anniversary I have gone back over the diary and corrected a few typos, tried to clarify some specific events and passages. As far as the decisions that were made at that time, the number one question people have had is, would I have done anything differently, both during this tragedy and before. As far as actions during these fifteen days, I have said and continue to feel that we did everything possible for David. In fact, we went above and beyond the “standard of practice” for David. After the memorial service I requested all documentation from the hospital, and reviewed it for two months. I called some of the doctors, and talked to doctors and professors about clarifying specific items in the notes. My conclusion is that some doctors, on their own, went beyond “standard practice” and prescribed advanced medications and procedures in an effort to save David. At two points in David’s care I requested experimental tests that I had read about in the literature in order to give a clearer picture of David’s condition. The conclusion I have come to is that even if we had lived a few blocks from the City of Hope and David was brought there instead of Mission Regional Hospital, the outcome would not have been different.

As far as the time before the tragedy, in reviewing the actions by me, family members, school and business associates, and David himself I can find nothing that could have been done that would change the outcome in any meaningful way. While in hindsight some of David’s “symptoms” such as being tired might have triggered an earlier discovery of the disease, my assessment is that these so called symptoms were so mild that jumping to that conclusion that a perfectly healthy 24 year old had a deadly disease made no sense at all. Even if someone, a family member, friend, business associate, or David himself were paranoid and implored him to seek immediate medical attention two, three or four months before the tragedy, the outcome would not have been different. I researched Acute Biphentotypic Leukemia (ABL) extensively during, and after David’s hospital stay. The bottom line is that the two year survival rate for someone with his form of the disease and at his age are from 0 to 3 percent, and I could find no study where the five year rate was above 0 percent. ABL is a disease without a cure. Just last week I read the blog of a mother whose 35 year old son had just succumbed to ABL. He was diagnosed earlier because the particular way the disease attacked him, but even with that, after six months of chemo he did not achieve remission. For the treatable Leukemia’s remission is usually

reached it one month, sometimes less. That scenario is the best we could expect if things had been different for David.

Thank you for reading the story of David's fight with cancer.

Jack A. Allweiss
December 2006

Part One: LIFE BEFORE CANCER

Hello, I am David Allweiss, and I am a cancer survivor.

I was diagnosed on November 29, 2005 with Acute Leukemia at Mission Community Hospital in Mission Viejo, California.

Today is Saturday, December 3rd, 2005 at 3AM. I am in a coma, so my dad is writing this for me. He is with me now. He will go back and tell you the story up until today, the 5th day since my diagnosis.

The story starts on Sunday night, November 27th. Meghann, my wife, and I had just come back from my parent's vacation home in Indian Wells, California. We had spent the Thanksgiving Day weekend in Indian Wells with our families; my dad and mom, my brother Jonathan, Meghann's mom Julie, and her sisters Shana and Heather. We had a wonderful time. I went bike riding with my dad on Thanksgiving Day. We did ten miles. Near the end I was a little tired, but not seriously. After we returned Meghann and I did a little shopping and then helped my mom get the dinner ready. We had a great dinner that featured turkey with all the fixings. Unfortunately my mom got sick right after dinner. She was hit with the bad flu going around. Julie told us that she had gotten the flu a couple of weeks before and was sick for three days with fever, vomiting, and diarrhea. My mom had the same symptoms. My dad took good care of her, checking up on her every hour or two.

On Friday my mom was still sick. Meghann and I slept in a little. Julie and the girls went shopping for a bathing suit, and my dad went on a bike ride. After lunch Shawn Knight, our family masseuse in Indian Wells came by and gave Julie, Meghann, and my dad massages. We spent the rest of the afternoon relaxing. My dad took us all out to dinner at Don Diego's, a Mexican restaurant near our home. My mom was still very sick and stayed at home.

Saturday morning my dad and mom drove back to their home in Mission Viejo. My mom was a little better. Goofy, our cat, got out Saturday evening when Meghann's sister left the door open. Meghann was a little stressed, but I told her the cat would come back. About an hour later Goofy came back. That evening we ordered pizza and everyone enjoyed it.

Meghann and I stayed in Indian Wells until Sunday morning and saw Julie and Meghann's sisters off on their way back to Utah. Meghann and I cleaned the house and I called my dad about the alarm system. It was complaining about a low battery. My dad said it was OK, and that he would take care of it the next time he was out. We collected Goofy the cat and headed home to Las Floras.

We left about 1:30PM, first we stopped at the auto parts store for some parts I needed to work on Meghann's car. I drove all the way home to Las Floras. Traffic was heavy. During the trip Meghann and I talked about all the things we had planned. We passed the Palm Springs Tram exit and talked about going up the Tram. We laughed when she reminded me that the last time I took her on a trip to the Tram my Firebird caught on fire. We talked about going to Catalina Island. Our friend Matt Miller and some other friends were interested in going with us to Catalina and we were going to get working on it after the Thanksgiving weekend. Meghann was also going to go to Utah to see her family. I was still undecided if I could break away from work. We got home a little after 4PM. I was tired.

Meghann made pot pie and I had a good dinner. We sat down to watch TV. My mom called and said she was better but my dad now had the flu and to keep an eye out for symptoms. About three hours later I began to feel sick. I told Meghann I was getting the flu and I guessed she was going to be next! I continued to watch TV a little but finally I went to bed. I was feeling bad.

Monday, November 28th

A couple of hours later, about 1AM Monday morning I began to vomit and have diarrhea. I had a fever. Meghann stayed up all night with me. She tried to give me fluids and a cool cloth but we did not have any Tylenol since I was rarely sick. Meghann called my mom in the morning at 7AM to let her know what had happened. My mom and dad came over at about 10AM with Tylenol, Pepto Bismol, Imodium, and Gatorade. I was running a temperature of 103 degrees. After taking the Tylenol, my temperature dropped to 102 within a half hour. I started to feel a little better. I saw my mom, but my dad stayed in the living room, he was still feeling very sick and did not want to risk giving me any more flu bugs. My parents left at about 11AM.

By mid afternoon I was feeling a lot better. I had drunk a lot of Gatorade and it made me feel better. I called the office and talked to John Schuetz and Jim Renzas. We talked about some business issues. I told them I might be back in the office on Tuesday, but Wednesday at the latest. I was tired by the time Meghann got home, and had a temperature, but otherwise I was ok. I asked Meghann about her day. She told me her

art teacher was having an art showing on the 10th of December and asked if I wanted to go, I said yes. A couple of hours later I was feeling a lot worse again. She took my temperature and it was back up to 103. She called my mom who advised her to give me more Tylenol and a cool cloth to get my temperature down. Within about an hour she called my mom and let her know my temperature was dropping back to 102. I went to bed about 10PM. Everything seemed to be going well and I went to sleep.

Tuesday, November 29th

About 1:30AM Tuesday morning November 29th I woke up. I started to feel really bad and somewhat disoriented. I started a bath because I felt too warm or cold. I went back to bed about 2AM after my bath. At 3AM I was still warm and started the bath again. Meghann came in and I was in the bathtub apparently sleeping. I was not responsive, so Meghann pulled me out of the bath. I woke up and went to go to the bathroom and passed out again. Meghann put me on the floor. Then I tried to stand, but fell down. Meghann caught me. Meghann asked me where I was. I told her I did not know, but I had to get to bed. She went to get the phone but I stood up again. Meghann called my mom, who told her to call 911 and that she and my dad would meet us at the Mission Hospital ER. I was drifting in and out of consciousness.

When Meghann called 911, the call was taken by the Medix night dispatcher who happens to be the brother on one of my best friends, and the son of one of my bosses at work, Mike Schuetz. The incoming call referred to a 22 year old male who was having extreme complications such that the Orange County paramedics transported me to Mission Hospital instead of the Medix ambulance. At the time Mike did not know it was me, but the next day he was shocked to learn he had handled the dispatch call on me. It was only a few minutes until the paramedics arrived. Unfortunately by then I was going in and out of consciousness. I was having trouble breathing and getting enough oxygen. I did not know it at the time but my immune system was knocked out of commission and my body was going into septic shock, flooding my blood with toxins that were crowding out oxygen and other vital blood components. My body was at the first stages of shutting down. The paramedics came and got me onto the bed and began pushing glucose and fluids. My sugar level was 66. My breathing was fast and my pulse weak. After the paramedics got me in the ambulance I became conscious a couple of times. I asked where Meghann was and they told me she was in the front of the ambulance. I was happy about that and decided to rest. I slipped into a coma so the rest of this story is now the result of observations of others.

I arrived at the hospital at a little after 4AM. They moved me to the ER. The toxins had reached a critical level and my heart stopped and my organs were shutting down. In the ER, Dr. Matt Kaplan called a code blue. He was able to get my heart started after only fifteen or twenty seconds. They thought things were going to get better but I continued to go downhill. My heart stopped again, this time for ten minutes or more, but by then they had me ventilated, were doing CPR, and had me on oxygen. My heart started again, but I was in deep trouble. I was on a full time ventilator now. They took a blood test and my

levels were completely out of whack. My O2 saturation had dropped to 67%. My blood was anemic and I had very few white cells or platelets.

During this time the chaplain, Roger Rustad came to the ER. He and Dr. Kaplan talked to Meghann and my parents. Dr. Kaplan told them the outlook was grim but they were not giving up.

After about an hour and a half in the ER they determined that I had a chance to make it. So I was admitted to the hospital Cardiac Intensive Care Unit (CICU). Dr. Luppi was the admitting physician, and Dr. Rovzar was the Intensive Care specialist. They would be the initial core of my team.

After being in the CICU for about a half hour, Dr. Rovzar went to see my mom, dad and Meghann. He was kind, but honest; my situation was touch and go, critical. Now, it was minute to minute. If I could get past that it would become hour to hour, then day to day. We all needed to pray. My wife and parents took it very hard; there was a lot of crying. But they pulled it all together and decided to support me in my fight. I also was waging a battle. The bugs had gotten the upper hand, but now I had the help of my doctors and the hospital. My organs had shut down because of the sepsis, but now they gave me artificial ones to help get me through. My immune system was overwhelmed, but I now had the best drugs in the world to wage the battle of the bugs. My circulatory system was fragile, but now I had powerful drugs to help bolster it.

At about 10AM they let my mom and dad and my wife Meghann see me. It was touch and go. My pulse was 150, my blood pressure was 80/40, and both numbers were not stable. Sometimes they would shoot up and sometimes they would fall. My blood was anemic so my oxygen level was about 80% now. They gave me more whole blood and other fluids. Slowly, by the late afternoon things began to change. I was fighting and winning, little by little. My heart and respiratory rates became more stable. My oxygen level climbed back up to near 100%.

By Tuesday afternoon we still did not know why this had happened to me. Dr. Rovzar concluded it was sepsis but could not find a source. Also, my blood chemistry did not match a classic case of infectious sepsis. My white cell count was very low. Dr Luppi decided to call in a hematologist who also was an oncologist, Dr. Nagasawa. My dad talked to Dr. Nagasawa on the phone about 3PM. The doctor wanted to do a bone marrow biopsy. This is not a difficult test. It is done by sticking a needle into the pelvic bone and drawing out some marrow. My dad was curious why Dr. Nagasawa wanted to do the test. Dr. Nagasawa wanted to test for leukemia. My dad was questioning the reasoning. I had been healthy; I had gone on a long bike ride with my dad that weekend. I was healthy! Dr. Nagasawa had his doubts also. The blood work did not show any cancerous cells in the blood itself which are often found. Up until then all attempts at finding the root cause had led to a dead end and there were other rare marrow diseases that could be tested for. So my dad signed the consent form for me and the people from the pathology lab came at about 4PM to draw the marrow.

Dr. Nagasawa called my mom, dad, and Meghann together to let them know the result of the tests. Dr. Luppi accompanied him. The test for leukemia was positive! This complicated things even more. It would be touch and go for me even if my immune system were in good shape, but now the mysterious reason for the anemia, low platelet counts, and low white cell count was clear. The leukemia had disabled my bone marrow, the factory for our important blood components. The doctors tried to be kind and give my family hope but they were also honest. I had a very steep road to climb. First, I had to beat the infection with an impaired immune and blood system, second I had multiple major organ system failures, and if I survived that I had to undergo chemotherapy treatment for the leukemia. Everyone cried. My mom said it was the worst day of her life. But after that the family pulled themselves together and dedicated themselves to supporting me in my fight with the infection and cancer.

I was diagnosed with Acute Biphentotypic Leukemia on Tuesday, November 29th. Now I am a cancer survivor. LIVE STRONG!

(The story concludes in part two).

Part Two: LIFE AFTER CANCER

Meghann and my mom and dad stayed with me the rest of Tuesday. At about 11PM Meghann and mom went home and dad stayed the night. He talked to me a little to give me encouragement but mostly just tried to let me rest and watched over me. I had two nurses around the clock. One was primarily in charge of the dialysis machine, which was like a baby needing constant attention. The other was in charge of my meds. They worked together and helped each other out. If a dialysis effluent bag was full and the dialysis nurse was not around, the other nurse would change the bag to keep the machine going.

That first night in the hospital I was fragile. Any little thing would send my BP and heart rate up or crashing down. The nurses did a great job moderating it and getting it back in line by using infusions and injections. In addition my blood numbers were not good. My BUN numbers (an indication of liver function) was off the chart. The PH of my blood was out of whack. They would give me a bolus of Bicarbonate to neutralize my blood, which helped my heart and other organs a lot. The doctors were called several times. By Wednesday morning I was a little more stable. My pulse began to drop and my pressure began to rise. My blood chemistry began to improve.

Wednesday – November 30th

Wednesday was an up and down day. I was improving slowly. Dr. Pan, my internist examined me. My digestive organs were still not working, but he told my dad that was to

be expected at this point. I needed to get the infection over with and my body chemistry back in balance. He felt after that the digestive system would begin to function.

Wednesday afternoon Dr. Luppi ordered an EEG and asked Dr. Ali Elahi to examine me. Dr. Elahi came by at about 4PM, took a quick look in the room, and began speaking to my family who were present. He told them that I was basically a vegetable. His assessment was that I suffered severe bi-lateral apoxia of the brain. My mom and Meghann began to cry and ran from the room. My dad stayed. My dad asked him how he came to that conclusion. Dr. Elahi said he had read the chart, which said I was not breathing at home or in the ambulance, so obviously I suffered many minutes without oxygen to the brain. My dad asked him if he looked at the EEG and he said no. Then my dad asked him how he could draw such a conclusion. Dr. Elahi said he could tell by "looking". Dad suggested he look at the EEG. My dad had looked at the small EEG machine that did not give a lot of detail, and found a relatively normal pattern with an overlay of epileptic pattern. Some people live normal lives with that pattern. In injury it is not uncommon for that pattern to appear and then subside. My dad insisted Dr. Elahi look at the EEG. He did for a few minutes. Meghann had returned to the room. Dr. Elahi then came back and said his assessment was born out by the EEG, severe diffused brain damage. Meghann got upset, had some words with the doctor, and left the room. My Dad knew a little about this because when he was in graduate school he had been a biomedical engineering major for a while. He read EEG's. First, Dr. Elahi mischaracterized the record. I did get oxygen in the ambulance. My heart did stop in the ER, but I was getting CPR and other support. Second, Dr. Elahi made a FINAL pronouncement one day after the incident. Finally, Dr. Elahi was very insensitive, so my dad asked him to leave. My dad talked to Dr. Luppi and asked for a new neurologist. It took two days to get one, and we had to go to Irvine. On Friday Dr. Luppi called my dad and said he had gotten Dr. Kristin Leuck, a young doctor who gotten her MD from UCLA, and did a special internship on EEG at UCI. She came in and reviewed the record carefully. She ordered a new EEG.

Other than the Elahi incident nothing else dramatic happened on Wednesday. I just worked very hard to get better, and I got a little bit better. My family was a little down from there discussion with Dr. Elahi, but they perked back up. My dad did the night shift again. There were a lot of adjustments to bring my blood pressure back up. Nurse Rita was very experienced and felt one of the newer drugs used in heart surgery would improve my pressure better than some of the older drugs being used. She called the doctor and got him to approve the drug. After I got that at about 1AM my pressure began to go up. By the early morning my systolic pressure was up over 100 on a consistent basis.

Thursday – December 1st

By Thursday I was better still. My pulse was now around 110-120, still too fast, but my BP was steady most of the time. If I was stimulated I would still loose control. When you're sick like I am it takes a lot of effort to keep your system balanced.

Thursday during the day they began to try to remove some of the vasoconstrictive drugs. These drugs keep my BP up, but also have some bad side effects like limiting circulation to my extremities. Thursday was a see-saw day. Drugs would come off, and I would do OK for a time, but then my BP would drop and they would have to put them back on. They had given me seven units of blood by now, but my red blood cell count was beginning to stabilize. Platelets were still a problem. They would give me a ten pack and it would just disappear inside my body. Blood chemistry and gases continued to improve. I was pretty puffy from fluid retention, so they began taking fluids off using the dialysis machine. However, my BP would drop after a point, so they were limited in what they could remove. Meghann and mom stayed with me during the day, and dad came in the afternoon for two or three hours, and then came back at 11PM for the night.

Thursday night my BP shot up to 195 at one point. The nurses were reorganizing the drips when it happened. They were able to get my BP back to normal, but my dad told them he noticed then whenever they did a direct injection into the system, like a bolus, my BP would rise and I would react physically (tremor). The problem was that the injections were causing suction on the drips which would cause a spike in BP and other meds. The system was re-plumbed so that the drips went in on the carotid line and injections on the femoral line. After that it did not happen again.

Friday – December 2nd

I continued to improve. My blood work was better, my vitals were more stable. They began withdrawing BP meds and feeding me via IV for the first time. Dr. Luppi told my dad he found Dr. Lueck who would be in on Saturday for her first evaluation. She had ordered an EEG. They wanted to do a CT scan on me to see the status of my brain, but I was hooked to continuous dialysis. One of the nurses suggested that the next time the dialysis clotted, which required about 2 hours of down time that I be moved to CT scan.

Saturday – December 3rd

The opportunity to do the CT scan came Saturday just before noon. The dialysis machine clotted that morning so they began the move. It was tough. I still had 12 infusion pumps hooked up to me, and a ventilator! They need to make wider elevators in the hospitals now! My BP began to drop and fluctuate but I managed to stay out of trouble. We went from the fourth floor CICU to the first floor CT scanner. They managed to get me into the scanner and get a picture of my skull. They wanted to flip me and get a body scan, but my pressure began to drop again so they decided to pack me up and get me back to the ICU.

Dr. Lueck came in that afternoon and did an EEG, which she attended herself. She also reviewed the CT scan with the radiologist. The results weren't great, but could be classified as inconclusive. The bi-orbital pulse was gone from the EEG, the waveforms were consistent with someone being sedated, minimal brain activity. The CT scan showed some fluid and some blood in the brain, but not a lot. There was some damage but she was not sure how much.

Sunday - December 4th

By Sunday I had stabilized a lot. My BP was now pretty consistent at 130/80, and my pulse at about 110. I still had a lot of problems retaining platelets, so I was getting an infusion of them twice a day, but the numbers remained low. By late Sunday I was off most of the BP meds. Dr. Lueck called in and asked if the paralytics and psychotropic (pain killing) drugs could be withdrawn early Monday (6AM) so she could do an evaluation early Monday morning. I had a restful night.

Monday – December 5th

Monday would be a tough day. At 6AM they withdrew the pain and paralytic medications. My brain began to awake but it was disorganized. I began to tremble. Not violently, but more like a shiver. It would last a few minutes and then subside. Stimulation would also cause this reaction. Dr. Lueck came in about 8AM and evaluated me for about an hour. Dr. Rovzar was also there, as was Dr. Nagasawa. After the exam they met with my mom and Meghann. While my body was getting a little better, my brain was not. It appeared to Dr. Lueck that I had dispersed damage throughout my brain. Now it was not clear what the extent was, or how much it could heal. I still had cranial pressure which could account for some of the observed behavior. Mom and Meghann were pretty devastated. Things seemed to be getting a little better every day, but then this overshadowed it all. The rest of the day was pretty somber. My BP was a little high, so now they gave me nitro to push it back down. Wow, I went in four days from four of the most powerful drugs to raise my BP, to now having to control high BP! That was progress. But now that the brain meds were off, everyone could observe the tremors and they were a reminder that I faced a serious challenge with my brain.

Mom and Jon gave platelets today at the Red Cross. I should get them on Friday.

Mom and dad switched night shift today, mom was with me all night. Jon came by in the night for a couple of hours. It was good he was there. I miss him. Dad came back early Tuesday to talk to the doctors.

Tuesday – December 6th

Dr. Nagasawa came by early. He looked me over and looked at the charts. He told my dad that my body was doing better. However I was no were near stable enough to be transferred to City of Hope to begin treatment for my leukemia.

Dr. Rovzar came by at about 9AM. He told my dad that hemodynamically, I was doing better. I was off all the vaso drugs and was taking a little nitro to drop my BP. He explained to my dad that my pulse rate was still high because of the inflammatory reaction due to the sepsis still being active. As the inflammation subsided my rate should drop. I was having some trouble fighting the ventilator. Normally they would give some sedative drug, but because the EEG was due tomorrow they did not want to give me a

drug that would affect that. So nurse Charlene suggested they use Propofol, a fast acting but short lived sedative used in surgery. Dr. Rovzar was a little concerned because it is metabolized in the liver, and my bilirubin numbers were high. But there are always tradeoffs in treatment and I was getting very uncomfortable.

My dad went to get his Remicade treatment at 10AM. Meghann came then and talked to me. Dad came back at 12:30PM and told me Dr. Shiel and Maureen Welker sent there love and prayers.

My bed was getting uncomfortable for some reason; my head was not positioned right. Charlene noticed that and called the bed company. The man from the bed company came and found one of the inflation cushions was not right, so my dad and Charlene helped lift me up so he could position the cushion. It was much better after that.

Meghann kept me company the rest of the day. Several doctors came by later in the day. Dr. White the infectious disease specialist had no news. Dr. Nadar said my liver was still having problems. He said it was not uncommon for bilirubin to go up after an injury. It is a lagging indicator. My BUN has risen also, so they have to watch that. Dr. Toy came by and examined my skin. He prescribed some medication to help it heal and keep any infection from starting. My vitals were stable. Dad went home to get some sleep.

Wednesday – December 7th (Pearl Harbor Day)

Mommy came at 11PM so Meghann could go home. My night was OK, but not great. My fever returned, so Nurse Loraine tried to cool me down. I went up to 101.5, however by morning I was back to 100. Hopefully I won't get another infection. My dialysis machine stopped working at about 2AM. Nurse Loraine called Gambro to change the filter because it clotted, but by 4AM no one had come. She called three times. Finally at 6AM David from Gambro came in before his shift was to start to cover for whoever was not doing their job. He changed the filter and the machine was working again at 6:30AM, but I am behind in fluid removal again. Dad came again at 7AM. He and mom left to have a quick breakfast in the cafeteria. Dad was back at 7:30AM. The neuro-physiology lady who will be doing my EEG came by and began to get set up. She will be back at 11AM to run the test. I am hoping for the best.

After the tests the bed company people came again. The bed was bad again so they brought a new one. They switched me to the new bed and gave me a bath in the process. I feel much better now.

Dr. Lueck came by about 3PM and talked to my dad and Meghann. Unfortunately the news is not good for me. The test showed no improvement from my last EEG. The waveform is what is called "slow", meaning minimal brain activity. The sensory tests showed no reaction to sound, light, or touch. It appears I have been severely brain damaged. Dr. Lueck suggested we do another kind of test called a somatosensory evoked potential (SEP). This test shows if there is nerve pulse conduction from a point on the body to my brain. Dad asked her to proceed with the test. I will get it on Thursday.

My vital signs are stable, although my liver bilirubin numbers have been rising, which is not good. Other liver enzyme tests are good however. They are removing the catheters used to measure my blood pressures, heart rate, and temperatures.

Thursday – December 8th

I had a pretty good night. Nurse Rita was on duty and she and mom took good care of me. She covered my eyes because they have been open a lot. I cannot really control them well.

Thursday in the morning Dr. Rovzar came by and talked to my dad. My liver was better today. He would begin feeding me since my digestive system seemed to be working again. He said as far as my body, the healing process was going well. He felt that my lungs were getting better and that I might be able to go off the vent in a couple of days. However my blood component situation continues to be bad because of the leukemia. I needed more whole blood because I don't make red blood cells. My white cells are low, and I don't make platelets and continue to need regular infusions. If I don't wake up soon these complications will have dire consequences. My Dad found another diagnostic for my brain; it involves computing a quantitative ratio of the white matter Housefield units to the grey matter. The paper was originally published by researchers at the University of Massachusetts in 2000, with an update in 2004. It seems to be a strong predictor of outcomes. Since I had a CT scan, my Dad asked that the calculation be made. Dr. Rovzar was going to talk to radiology. My Dad also gave a copy of the article to Dr. Lueck.

Dad talked to Dr. Chen and Nadar. They were pleased that the bilirubin and BUN numbers were stable to down. Dr. Bailey also came by. The infectious lab still had not found any sign of infection in the blood and skin samples. They would continue me on antibiotics and antifungal drugs since I had a very low white count. They gave me Nupogen to stimulate white cell production, but the leukemia was really hampering any effect.

Thursday afternoon at about 1PM the neurology department came by and did the SEP test. My dad left after the test was started since Meghann had come. He asked Meghann to call when Dr. Lueck came by. She called him at about 5:30PM.

Dr. Lueck had bad news. The SEP test showed no conduction into the cortex. The nerve impulse was there up to the spine electrode, but nothing past the base of the brain showing cortical response. Dr. Lueck pointed out that recent studies show that people with anoxic cortex damage who are absent cortex signals have a very low probability of awaking. Dad checked the literature and the probability of awakening for children is about 7%, for adults about 0%. Since I am only 22, my probability is maybe 2-3 percent. Dr. Nagasawa came by and he and dad discussed the leukemia status. They agreed that in my current condition treatment for the leukemia was not possible.

Meg and Dad were very upset. Meg went off with Mike and Matt for some dinner and to settle down. Dad stayed with me until 8PM when Nurse Rita was going to clean me up, Meg came back at that time with Mike and Matt. Dad told mom when he got home, and of course she was upset. Honestly it is not looking good but I will keep trying to get better.

Friday – December 9th

My night was quiet. Mom and Nurse Rita were with me. I am pretty stable.

Mom was feeling sick and went home at 6AM Dad came at about 7AM. My dad has an appointment with Dr. Lee at 8:45AM, so he is going to be gone for a little while.

Dad and Dr. Rovzar talked about my condition. Dr. Lueck will be doing the CT scan evaluation that my dad found in the literature this afternoon, so we will have more information on the cortex this afternoon. After that my dad said he will ask Dr. Lueck to do one more SEP test, with the Propofol sedative withdrawn. Then they will decide what treatment plan to pursue.

Dr. Lueck came by at about 4PM. She said the terminal she had on the 4th floor to look at CT scans did not have the software to do the analysis in the paper my dad had found. She went down to Radiology where they had a more advanced computer. She came back up about 45 minutes later and reviewed the results with dad. The results were not good for me. The control CT scan (of a known good health brain) measurements fell within the range predicted by the study, so my dad knew the measurement was being done correctly and there were no problems with the CT scanner. My measurements fell well below the cutoff for severe brain damage (the cutoff in the research was a ratio of 1:1.18, mine was about 1:1.02, healthy is about 1:1.4). I was below at all three brain “slices”. The combination of these two quantitative tests predicts not just brain damage, but death. The brain is too damaged to even sustain the body. In addition I have the cancer, which continues to spread. Over 90% of my bone marrow is now cancer cells.

It was clear now that I suffered severe brain hypoxia in the minutes and hours following my heart stopping in the ER, and possibly before or after, on November 29th. I guess I have been writing this from heaven, since my soul left my body on that day. My dad and Dr. Lueck agreed to do one more SEP test, without the sedative, just to make sure. But I am at peace now. I am glad my body survived a few days to give my family a chance to mourn and say their goodbyes. I’ve had a great life. I could not ask for a better family, friends, or wife. I would have liked to have had a chance to experience more of life, but that was not my fate. Please remember me always.

Saturday and Sunday – December 10th and 11th

No real change in my condition. My dad discussed the situation with mom and Meghann. They were grief stricken, but understand the situation. Everything that could be done has been done. It’s no ones fault. This was my fate. This disease, Acute

Biphenotypic Leukemia, is terrible in adults. What caused it? No one really knows. It is thought to be a genetic fault triggered by some external environmental insult. Some genetic markers show a better possible outcome for treatment, but none have been implicated in the disease process itself. It is rare, especially in my age group. For young kids the remission rates are high, almost 90%, but for adults they are closer to 10% or less.

My BP has been moving around a lot. My pupils on Saturday night showed asymmetric dilation. Mike was at my side and the nurse called the doctor with the observation. Mike asked if I wanted another CT scan, but my dad decided there was no point. The problem was due to either additional damage to the brain stem or pressure, but there really would be no treatment other than brain surgery, and I was not a candidate for that due to my unstable condition. My temperature went up to 103 early Sunday morning (3AM), they gave me a bath and it dropped to 99. Either I had some reaction in my body or the regulation in my brain stem is failing. My condition is now deteriorating.

Early Monday morning I will be taken off the Propofol for an hour or so, and then Dr. Lueck will do one more SEP test and clinical exam. After that my family will assess the future treatment of my body.

Monday – December 12th

They redid the SEP test today. I was shaking a lot because the Propofol was off, so it made it hard to get a reading on a couple of probes. After a while they got the information and it confirmed the earlier test. Dr. Lueck examined me again off the Propofol, and the clinical evaluation was the same. I began having stomach bleeding, and I got another infection. The problem with leukemia is I have no immune defense and the leukemia continues to spread.

Since my marrow was now failing to produce any blood components, I needed constant infusions. In addition, I had a temperature again and needed strong antibiotics, which themselves were damaging to my organs. My digestive system, which had begun to work at the end of last week, was now shut down again, so I could not be fed, even with a tube. Monday night and early Tuesday I had a couple of episodes where the nurses thought they would lose me, but I hung on.

Tuesday – December 13th

Today the family will meet with the doctors to discuss what treatment protocol should be followed. My family now understands that I am not really here anymore, and that my body is being ravaged by the cancer. My brain and many of my organs are no longer functioning. They will ask the doctors to institute what they call a comfort protocol, withdraw all the machines and let my body pass naturally. I lost my fight with cancer, but others struggle on, please support them if you can.

David passed peacefully on Tuesday, December 13th at 9:15PM with his family and a close friend in attendance. The last thing the family was talking about before his passing was the wonderful memories from his wedding, just four months before...

Jack A. Allweiss
Father

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