

**A Marathon of Anguish and Grace**  
**The Journey of Our Son's Bone Marrow Transplant for His**  
**Adrenoleukodystrophy**

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## ***An Opening Word***

Life had been routine. My career had been such that my wife Sue and I could choose it to be so to raise a brood of three in an area 40 miles outside of Detroit, Michigan. People say stability is good for children. I suppose what that implies is that change causes uncertainty, which in turn calls for adjustment. Inability to cope with the harshness of life could lead to a feeling of out of control. As a husband and a father, I certainly had to face the most exhausting crisis of my life—the diagnosis of my son’s Adrenoleukodystrophy and the subsequent search for a therapy or perhaps even a cure.

However, we were not alone. Humanity, community, friends and family had sheltered us physically and emotionally. People today still express their interest and concern to members of my family about Kyle. I know they will keep doing it until they see with their own eyes or are told that my son has reached his full recovery--the degree of which or even whether he will live can only be hoped but no one knows for sure.

As for the struggles within, I had chosen to write this book to capture my personal feelings as events unfolded. My initial motive was pure: I just wanted to reveal my inner self to help others to face their own life or death crises. I chose to write it in the present tense because I wanted the reader to see and feel what I sensed at the very instant of every happening. I wanted my journey to be alive and kicking.

The days and hours I spent in Kyle’s hospital room presented the perfect opportunity for writing. Its therapeutic value had been enormous as well.

My colleague Les Osenkowski at DaimlerChrysler has been the lone ardent supporter for my endeavor. His frequent encouragement gave me the fuel to keep going when I was wavering. In fact, he is doing it again to urge me to publish it. Reading by a few others such as Ruth Muir, Ellen Rothfeld and the Sleeping Bear Publishing told me that the content was compelling. My gratitude goes to them as well.

May, 1999

## ***1 - The Coming Storm***

The phone rings in my office in Plymouth. It has been just over a month since a part of the Jeep Engineering moved from Detroit to this new location. Sue is on the other end of the line. I find it odd because she is normally too busy to call while working in the kitchen at the Brighton High School.

“Dr. Parrinello called this morning to tell me what the specialist found on the MRI. It is bad, terribly bad. He says Kyle has Adreno...leuko...dystrophy, but he should see a neurologist right

away,” Sue tells me in a hesitant but calm voice.

“What is it?”

“It is a disease that affects the brain and the Adrenal Gland. It is so rare that Dr. Parrinello had to look it up.”

“Are we going to lose him?” I want to get to the point quickly.

At that moment, Sue breaks down sobbing. Tingles gush up to my head from my spine as my heart begins to pound. Anticipating the affirmative, my mind goes blank. Even the ticking of the time seems to have stopped. That pause is like an eternity. I wish it could remain so, so that the answer would never come.

“From what Dr. Parrinello could learn, he might live a few more years--probably not beyond his late teens,” continues Sue after she regains her composure.

Wanting to wrap my arms around her and fighting back tears, I manage to say, “When I get home, I’ll get on the Internet to find out more about this Adreno...stuff.”

It was a little over seven years ago that Kyle came to us as a two-year old from an orphanage in Seoul, Korea. Of all the boys there, someone picked him out for us. Was it by chance or Divine Providence? I have always believed that God oversaw the matching process. He has entrusted Kyle to Sue and me. Obviously, in my wildest expectations, I have never expected to face something like this. I wish we could have been warned. If we had been, would we have adopted him? Yet, someone on this earth has to. It is up to us now to get ready for the fight of our lives.

I’m new to the world of Internet--having just recently signed up with ISMI located in Howell, Livingston County. To my amazement, when I type in the search word, it yields screen after screen of articles related to Adrenoleukodystrophy (ALD). It is a degenerative genetic disorder of the myelin of the brain cells, which would cause the brain to short-circuit upon onset. One can quickly lose one’s motor control and eyesight towards a quick death. Several articles are about the movie Lorenzo’s Oil. From the synopsis, this movie, starring Nick Nolte and Susan

Sarandon, seems to be a docu-drama about ALD. Apparently, it has been used as a popular case study for students and teachers alike. Sue is a movie buff. She thinks she has seen the movie but can only vaguely remember that it is about a sick boy. Still dazed, neither of us feels the urgency to rent the movie. After all, the diagnosis still has to be confirmed.

## ***2 - Having Doubts***

Our son has frequent headaches; often so severe as to cause vomiting. Because of that, Sue took him in for a CAT scan in early September. Something was detected then, but the diagnostician was not sure enough to disclose it to our family doctor, Dr. Parrinello. To zero in on the problem,

an MRI would be needed. For that Sue had to drive Kyle to Providence Hospital in Novi. I remember how proud she was about his steadiness and calmness throughout the long, strange procedure. The machine made different loud clicking sounds for about 45 minutes. Because of the length, kids often have to be sedated. From early on Sue has trained our children not to be afraid of medical procedures. Once again it had paid off.

After the initial shock wears off, Sue and I are now ready to see the movie. Sue is surprised to find it at the first place she tries: Front Row Video. However, I sense that, like me, Sue is somewhat hesitant to stick it in the VCR. The thought of watching our future struggles play out in front of our own eyes would be eerie.

The children are all in bed. Sue picks up the video from the end table and moves toward the VCR. Time seems to slow down as my nerves begin to flash. She appears to advance one frame at a time. The snapping sound the tape door shakes me out of the time warp. Sue's face has turned pale. I know she is as nervous as I am.

The movie is about a couple's relentless drive to find a treatment for their bed-ridden, seizure-prone son Lorenzo, who is quickly losing his eyesight and the control of his motor functions. When exhausted in caring for him, his parents mortgage their house in order to hire a full time live-in nurse from abroad. In the mean time, all kinds of diet are tried to improve his symptoms but to no avail. Finally, through hard questioning of the medical staff and long hours of studying at the library, Lorenzo's economist father zeros in on an oil mixture, which is yet to be synthesized. He locates a soon-to-retire chemist abroad just in time to synthesize the oil in the laboratory. This new discovery, the Lorenzo's Oil, is tried on Lorenzo. The very long chain fatty acids are dramatically reduced. And, Lorenzo's symptoms improve some.

The movie leaves us gasping for air. Sue and I gaze at each other in awe of the couple's courage, persistence and intelligence. I wonder how the story might have turned out if the chemist had not been found. However, our son is an ordinary boy, not at all like Lorenzo. We don't see any

similarities at all and begin to seriously doubt the diagnosis. Is it possible that Kyle has a yet unknown Leukodystrophy? Or is it like hearing the rumbles but not seeing the storm? The more we talk, the less we are convinced of the diagnosis.

Sue gets an appointment to see Dr. Trock, a neurologist. He performs a series of tests to assess Kyle's neurological conditions. No significant deficiencies are found. A blood test is ordered to determine the levels of the very long chain fatty acids. Sue then takes him to an endocrinologist for an Adrenal Gland analysis. Again, it is negative. Next, we are referred to the Detroit Children's Hospital to explore our options. Dr. Nigro, the head of the Pediatric Neurology Department, is very terse with us. He says the only known therapy for ALD would be a risky bone marrow transplant whose long-term effect is still being studied. When we mention Lorenzo's Oil, he responds emphatically that it is neither a cure nor a therapy even though it does lower the very long chain fatty acids. However, he leaves it up to us whether to put Kyle on the oil diet. The oil itself can only be obtained through a prescription from the Kennedy Krieger Institute in Baltimore, Maryland.

Since the oil should do no harm, Sue and I are ready to go to Baltimore. Besides, a thorough evaluation by their world-renowned neuro-genetic research staff should dispel any doubt regarding the ALD diagnosis. Drs. Moser and Raymond have written extensively in the field.

### ***3 - The Clincher***

The trip to Baltimore is all set. The three-day and two-night stay in the hospital is free. Polly, the nurse coordinator, says that she would arrange to have a room reserved for us at the near by Ronald McDonald House. In the mean time, Joyce and Shila each have found a family they feel comfortable staying with. Our dogs, Ricky and Torrey are going to a kennel.

The mood for the trip is somber, though we try to treat it like any other. Again, I am torn between wanting to know more and fearing for the answers. Kyle has brought enough games to conquer the monotonous 10-hour drive.

Because of the Thanksgiving traffic, the trip to Baltimore ends up to be two hours longer. Finding the Ronald McDonald House turns out to be the toughest part of the trip. Where I come from the term *nearby* means a few blocks, not a few miles. After driving around in the surrounding slums for what appears to be an eternity, we finally pull in a fire station for help. It just so happens that one of its employees is going home. He volunteers to lead us in the right direction.

When we check in at the RMH, the house manager Willie tells us that there is no reservation under our names. Panic sets in as she tries to find a room. After a long wait, one on the second floor is finally ready. Then she proceeds to explain the house rules to us. This trip has not been easy. We are ready to go to a nice restaurant to relax for the evening.

Next morning, we decide to drive to the hospital rather than take the shuttle. Kennedy Krieger is on the corner of Johns Hopkins Medical Center. However, they use its facilities to house patients for research. As such, Kyle is assigned to a shared room in a special pediatric wing.

His roommate turns out to be a teenage boy from Sweden. He has an unknown degenerative neuro-genetic condition, which causes frequent seizures. The Cederroths came to KK after having tried many places in Europe. Of the four children, only the oldest girl is free of any symptoms. Sue and I are awe-struck by their quest for the correct diagnosis and their *business as usual* attitude. In every difficult situation, someone somewhere is facing a tougher one. There is a will; there is a way.

It has been a busy morning at the hospital. While waiting, Kyle is introduced to the video games in the room kitty corner from ours. A blond young man, who can easily pass for an intern, hurries into the room, apologizing for being late. He introduces himself as Dr. Raymond. His youthful appearance definitely understates his expertise. The first thing he mentions is that the blood analysis Dr. Trock ordered was done by KK. The results are consistent with those found in ALD.

He then gathers some background information about Kyle and proceeds to explain the program to Sue and me. It consists of a series of blood tests, physical examinations, MRI's, psychological tests, nutritional evaluations and interviews. Then Dr. Moser comes in to meet us.

“How was Kyle diagnosed?” he asks in a low, gentle voice.

Sue tells him our boy's story while he listens with a grandfatherly grin.

When he hears that Kyle is from Korea, he interrupts by saying, “I just got a fax message from the Korean ALD Foundation this morning. I'd like to give you a copy. Quite a few of their boys are on the Oil.”

His visit is brief and appears to be only ceremonial. I realize then that the clinical work is primarily done by his staff.

Our son has not been told the severity of his disease, but I often wonder if he has any inkling. Hitherto, we have been careful about what his ears might pick up. To him, the day's events are merely distractions between Super Mario games. That boy is neither stressed out nor bored. I volunteer to stay with him that night since Sue is a light sleeper. Sleeping in a chair that looks like a cross between a Danish and a Naugehide Lazy Boy will be a fresh experience for me. Sue is leery of going back alone to the Baltimore Ronald McDonald House though. The walk from the parking structure in the dark scares her. However, she feels more at ease with the suggestion that she send for an escort from the RMH.

I wake up many times that night because of the frequent medical attention needed by the Cederroth boy. Finally, I decide to walk the empty hospital halls at 5 a.m. and to get a newspaper. In the lobby, I notice a banner touting the #1 rating of the hospital--a fact I did not pay attention to earlier.

Dr. Cox, the psychologist, is introduced to us. She will conduct a number of tests on Kyle, lasting more than half a day in total. There is a special quality about her that puts both adults and children at ease. Her speech is gentle, deliberate and considerate. Above all, she explains situations and behaviors in a positive and non-judgmental way. Somehow in her presence, time does not seem to exist.

The program is near its end. Dr. Raymond calls Sue and me into a pediatric conference room. We each grab a little chair to form a small triangle. The last time I did this was in Kyle's third grade teacher-parent conference. I keep staring at Dr. Raymond, hoping to pick up a clue or two about what he is about to say.

“I am on the fence whether to recommend a bone marrow transplant for Kyle, but I have come down on the side of pursuing it,” starts Dr. Raymond. His eyes avoid making contact with ours.

Then he continues, “He definitely has some ALD signs and our MRI shows a significant amount of demyelination in his brain. His Adrenal Gland functions are normal. I am alarmed though by

his left side muscle weakness. His performance I.Q. is normal, but his cognitive skills are below-par. I'd recommend Lorenzo's Oil to lower the levels of his blood fatty acids. As you know, the Oil is not a cure but it might help him."

"He should also be on a low fat diet," Dr. Raymond adds. Telling the parents that their child should go for a risky procedure is an uncomfortable task. Dr. Raymond's mannerism definitely reflects that.

"Where should we take him for the bone marrow transplant?" asks Sue.

Feeling a bit more at ease, Dr. Raymond answers, "Minnesota has done the most of anybody, more than we have here at Johns Hopkins, but the procedure is practiced by so many hospitals that I'd let the convenience factor decide for you as long as they have done enough cases."

"What is the outlook of using BMT to stop ALD?" I ask.

"We only have records going back 7 years. World-wide statistics show that 50% of the patients are doing well, and the other 50% either have not done well or it's too early to tell." My spirit drops with that statement.

"Is Detroit Children's Hospital O.K. for the transplant? It would be convenient for us," Sue wants to be sure.

"I believe they have done enough cases. I think it should be fine," Dr. Raymond concurs. He ends the session by telling us that a nutritionist will meet with us to go over the diet.

Our son is a big boy. He is in the 90 to 95<sup>th</sup> percentile for both height and weight. The dietician has expected a much higher calorie intake than our dietary records. She proceeds to write down a detail diet plan for him, urging us to cut down on fat and sugar nonetheless.

Our boy is a picky eater. Besides, his stubbornness is legendary. Armed with the diet instructions and the Oil, Sue and I are ready to test his reaction and our resolve. On our way back to Michigan, we pull into a Burger King in Breezewood, Pennsylvania. The first thing we look at is the fat content of the menu items. Sue orders a BBQ BK Chicken Sandwich for him. Of course, he refuses to eat it. After threatening to leave as soon as Sue and I are finished, Kyle finally takes a few bites. We have just added a new source of confrontation to our family dynamics.

#### ***4 - Getting Down to Business***

Sue bears the brunt of enforcing Kyle's daily diet of 4 tablespoons of Lorenzo's Oil whose smell resembles that of a 10W lubricating oil. I must admit that drinking oil is a bizarre ritual. After one week of experimenting, Sue settles on spoon-feeding warmed up Oil at dinnertime with water, juice or soda as a chaser. It has easily added 10 to 15 minutes to Kyle's evening meal.

Finding a variety of low fat foods that he is willing to eat takes a bit longer. 25 grams of fat a day is difficult to stay under. When necessary, only a small amount of walnut oil or GTO (Glycerol Trioleate Oil) is allowed in cooking. We manage to avoid red meats and substitute them with lean turkey. Fish is good too. He seems to enjoy the extra attention. Slowly, the low fat diet becomes an institution for the entire family. As a result, we are all eating much more healthily.

It is now the end of 1997, and we have yet to receive the written report from Dr. Raymond. We are waiting for it to start the bone marrow transplant in Detroit. It has been 30 days since the start of the Oil diet already. Following the diet study requirement, the first sample of his blood is sent to a laboratory for analysis.

An appointment with Dr. Steve Abella of Detroit Children's Hospital is finally made knowing that the report is on its way. Dr. Abella is a pediatric BMT physician. The visit reminds me of going to a new school, full of anticipation and uncertainty. After we get off I-75 in downtown Detroit, a hospital sign pointing to the right before Baubien Street assures us that we are near our destination. A block away from the intersection is the parking structure. The clinic should be just a short walk from where we park.

When we arrive at the clinic, there are two other families waiting in the lobby. Two bald-headed boys are playing the games in the waiting room. I plunk down on the other side of the video machine while Sue checks in at the counter.

"This is my son, a miracle boy," says a woman on the other side the video, looking rather impoverished. She points to the one playing between us.

"Oh, how is that?" I ask.

"Well, he was so sick two years ago that the doctor did not think he would live. But look at him now," the woman can barely hide her excitement.

"He is really enjoying the game, and he looks good," I echo her sentiment.

"I prayed and prayed. I put my trust in God. He saved my boy," the woman says in a confident and unshaken voice.

I'm both envious and inspired at the same time. Will I be as trusting as she is? What will I say then if Kyle does not survive the transplant? Will I actually resent God or be an inspiration to others? A sudden feeling of spookiness comes over me. The woman looks real. So does her son. Can she be a messenger perhaps?

Dr. Abella is having a busy day. Our consultation is interrupted a few times by phone calls and other patients' needs. And yet, he always continues from exactly where he left off without skipping a beat--an amazing ability.

"We use chemotherapy for the transplant. With a 6-of-6-antigen match, the child's survival rate

should be around 75 to 80 percent. He will lose some I.Q. Kyle should still be a functional person. The transplant might add 15 to 30 years of life..." Dr. Abella speaks at a rapid firing pace.

I am willing to accept the odds but hate the I.Q. drop. Who will not want a longer life for their child? Is it just a matter of life or also a matter of quality? The prospect of supporting him for the rest of his life lies heavily in my heart. "What did Kyle do to deserve this? What did we do?" I murmur.

"The Business Office will tell you about the financial arrangement next. Have you met Ann Zdilla?" asks Dr. Abella as he ends our consultation.

"No, not yet," I shake my head.

"She has a lot of financial aid and fund raising information. I'll take you to her."

We arrive at a small office. "Hi, I'm Ann Zdilla, your business coordinator. We will contact your insurance company to find out about the transplant coverage. What Karmanos Institute asks for is a \$10,000 deposit to start the worldwide donor search. That cost is not covered by insurance. If it is not used up, we will return the money to you. If it takes more than that, we will ask for another \$10,000. It could even exceed that, if the search is long and difficult."

"What if I can't come up with \$10,000 right away?" I ask after taking a gulp.

"We will start the search with just a receipt of \$5,000. The balance should be paid soon after. We also have financial aid for lower income families. Let's see... Oh, your income is not on the chart... You make too much money to qualify," says Ann.

"We have many ideas about fund raising. Let me show you..." she continues as she opens a brochure to give us some possibilities. Then she hands Sue the materials.

"We'll see what we can do. It's going to take a week or two since I have to juggle a few things around," I respond thoughtfully as I run through some ideas in my head.

The business side of medicine comes down on me like a ton of bricks. I am already emotionally drained from knowing what ALD will do to my son. And now, I have to face the financial setback. Looking at our son, how can we not choose the best of the alternatives? The mood is dead serious on the way back from the visit as Sue and I go over the information we have picked up. The donor search is going to use up some of our savings. I have to liquidate a few IRA's. But we could also go public with our story, though I am not ready just yet psychologically. I have never depended on anyone since my college graduation.

Before sending any money to start the search, I first want to find out if there are any preliminary matches in the data bank. Kim McAlpine of Karmanos tells me there are about 30 4-antigen matches in the States. She says that that is a good number. Additional blood tissue testing of

these potential donors has to be done to determine the rest though. It is now early February in 1998. I send a check out of our savings. Then I liquidate an investment to come up with the rest.

## ***5 - Surrounded by Angels***

Sue has been very active in the Huron Valley Girl Scout organization. She tells me that the Girl Scout moms are eager to start fund raising for Kyle. All they need is a signal from us. I vacillate for a while. Faced with the unknown and feeling the tremendous financial burden, I finally swallow my pride and agree to go public.

Using their training, the Girl Scout moms begin to mobilize the community. We soon learn that Brighton Argus wants to do an article about our son. When our church learns of our story, our Senior Pastor Dr. Richard Alberta calls us to let us know that he will organize a congregational fund drive at the Cornerstone Evangelical Presbyterian Church. At the same time, Rich Ray, a Chrysler executive, brings the Argus article to work to begin another drive there. The news and the calls for help spread like a wild fire. There is a saying: Be careful, you may get what you ask for. Donations start to pour in. A trust fund account is set up at a local bank. WHMI in Howell and the Ann Arbor News announce Kyle's story as well.

The search at Karmanos begins with the largest registry: The National Marrow Donors Program (NMDP) located in Minneapolis. One by one, the possible North American possibilities begin to drop out when tested for their DR antigens. As the number dwindles, I want Kim McAlpine to look elsewhere around the world. The closest one is a 5-of-6 from a person in Germany.

Not willing to rely solely on the efforts at Children's, I begin to explore other avenues on my own. Since the HLA's (Human Leukocyte Antigens) are hereditary, my focus is to find a match among the Koreans. It just so happens that a few days earlier Darlene LaVere of Families for Children sent us an article about the Bauman family. Their struggle to find a marrow donor for their adopted Korean son Brian made many headlines here in U.S. and in Korea. I use the Internet to get their phone number. I find it on the first try along with their Pine City, Minnesota address. Steve Bauman, Brian's father, personally knows Dr. Kim Sung Im, Vice President of the Korean Marrow Donor Registry, but the Registry is not in the NMDP network. Right away I send a letter to Dr. Kim to look for a match in Korea.

While waiting for a response, another source comes to my mind: The Korean ALD Foundation. I have kept the copy of the fax that Dr. Moser gave me. Since ALD is hereditary, as a long shot, I try to reach the President of the Korean ALD Foundation, Mrs. Soon-Tae Bae. In the letter I ask her to possibly help us locate Kyle's biological family. My hope is to find a related matching donor among their members. She surprises me by calling me directly from Korea with a translator. She says she will check for me as soon as I fax her Kyle's antigens.

She calls back a week later to tell me that it would be difficult to pursue my idea. I wonder what she really ran into. Could she have found a relative but was asked not to disclose the information? What the heck, it was worth a try.

Then I find out that Darlene Lavere has arranged an Asian marrow donor drive at a Korean church in Ann Arbor. A second drive is scheduled for June at the Korean Presbyterian Church of Metropolitan Detroit in Southfield.

In the mean time, fund raising in Brighton is reaching a crescendo. Separate initiatives in Spencer Elementary, Scranton Middle and Brighton High School have been started. Schoolgirls sell bead animals on sidewalks. A Beanie Baby auction is conducted by the Downtown merchants. Collection cans with posters are placed in gas stations and stores. The Boy Scout sets up a spaghetti dinner at the VFW Hall, complete with a band of their own. Jaycees and the Lions Club chip in with donations as well. So do many friends and relatives. A golf tournament at Oak Pointe is planned in the summer to raise even more. Gerald Thompson, a renowned charity trust attorney in Northville, is hired to set up a trust for Kyle's medical expenses. Three Brighton women have agreed to serve as its independent trustees.

At this point, our search for a donor has reached Los Angeles, New York and Oregon. Sharon Sugiyama of Asians for Miracle Marrow Match (A3M) wants to use his story to promote new donor drives among the Asians in L.A.. Juling of New York's Cammy Foundation calls to ask for my permission to run a story on him. Holt International Children's Services in Portland, Oregon is eager to publish an article in their magazine about his BMT need. While all this is happening, I receive a phone call from Jethro Lai a member of the Detroit Chapter of Tzu Chi, a Taiwanese Buddhist Foundation. He wants to meet me to discuss how they can help. Using the fax number he gave me for the Taiwan Marrow Registry, I immediately forward Kyle's antigens there. The effort to find an Asian match and to urge more Asians to be tested has reached a frantic pace.

## ***6 - End of Road in Detroit***

Kim McAlpine is on the phone. From her voice I can tell that she is not calling to tell me the good news.

"We had a meeting with Dr. Abella this morning," she begins, "Since we have not found a perfect match in 4 months, he suggests that you pursue an experimental cord blood transplant where a perfect match is not required. We can't do the cord blood transplant here though."

"What is cord blood?" I ask.

"Cord blood is the blood in the umbilical cord of a placenta which is very rich in stem cells. It is even better suited for transplanting than the bone marrow," Kim patiently explains. Still wanting to leave the door open, she then continues, "But, if you wish, we can keep looking until we find a marrow match."

"I'd like to speak with Dr. Abella before my wife and I decide which way to go."

"Why don't I ask him to call you later today?"

“That would be fine,” so I end the conversation.

Dr. Abella calls me the next day. “I just spoke with Dr. John Wagner of University of Minnesota. That is why I did not call you yesterday,” says Dr. Abella, sounding apologetic and yet in a hopeful voice, “Minnesota does cord blood transplants. The other place is Duke University, but I don’t know anyone there.”

“Which one do you recommend?”

“In all fairness I can’t. I called Dr. Wagner because I know of him. Here is his phone number....”

Dr. Raymond of Kennedy Krieger has been my independent source several times already. He gives me two names to talk to, but he does not recommend one over the other: Dr. Kurtzberg of Duke and Dr. Peters of Minnesota.

The staff at Duke is very personable and accessible. When I talk to them, I feel like dealing with a family business. We have conversations daily. Minnesota, on the other hand, is slow to return my phone calls, much like dealing with a large corporation.

Little by little, I am getting a better picture of each center’s transplant procedure and their specialization. Duke has done the most cord blood transplants -- about 4 times more than anyone else. They use only chemotherapy to eliminate patient’s immune system before donor’s stem cells are transfused for grafting. Dr. Kurtzberg says that chemotherapy does not make a person sterile. For a boy she feels that to be an important consideration. However, Kyle would be only the second ALD patient ever at Duke. Minnesota, on the other hand, has done the most BMT of anybody. In fact, they pioneered the procedure in this country. They also have the most expertise in treating ALD and other metabolic diseases with BMT or cord blood. Drs. Krivit and Peters are renowned in the field. Minnesota tells me that the second chemotherapy compound, Busulfan, is a neuro-toxin. It should not be used in ALD patients because their brains are already damaged. In its place, they substitute it with Total Body Irradiation. The radiation level is halved to the brain and the lungs though. Dr. John Wagner tells me that their data, going back many years, show that radiation does not cause additional risks later.

To help me make a final decision, I call up Dr. Anderson of University of Indiana. Indiana is another cord blood transplant center. He unequivocally advises that, if he had a son with ALD, he would go to Minnesota because of their knowledge of treating it. That clinches the decision for me.

## ***7 - Go to Minnesota***

Dr. Peters suggests that we come to Minnesota for a consultation before getting on with the transplant. Sue and Minnesota settle on 2 days in early July. Since we have never been to the Mall of America, spending a few extra days in Minneapolis seems only natural.

Sue wants to take it easy by allowing two days to get there. It is only 3 in the afternoon when we approach Janesville, Wisconsin, our planned stop. A vote is taken to decide if we should go on. The consensus is to do so.

Half way across Wisconsin, we are back on I-94 again. The air conditioning in the Dodge Ram van starts to cut out. According to Sue, it has happened once before when she was driving back from Kentucky. We try first driving with the windows closed and the fan on high. Then we open the windows to see if that would be more bearable. Regardless, it is miserable either way. The only saving grace is the gradual cooling of the outside air.

Like previous trips, the crossing of the Mississippi invokes a feeling of entering a frontier, a place far less familiar. In the present situation, it is particularly true. Behind the excitement of discovering the Mall of America lurks the possibility of a split up family, separated by a distance of 650 miles and a time zone. In addition, Sue's mother needs around the clock care in her own home in Kentucky. We don't know how long her Alzheimer's is going to let her live.

It is between 8 and 9 in the evening when we pull in the University Best Western where Sue got a special hospital rate. The Fairview Medical Center is about 10 blocks away, too far for an easy walk. But there is a free shuttle service. The thought of the last family vacation with Kyle looms large in my mind. I want to do something spectacular with the whole family, and yet, when I think of the upcoming secondary medical and living expenses, I have to accept something much less.

Three days spent at the Mall is more than enough for my boy and me, even with all rides and games. Consultation at the University on Monday and Tuesday comes not soon enough. In fact, ever since our decision to go with Minnesota, I have wanted to start the transplant right away.

Dr. Peters is a tall, thin man with an intense set of dark eyes. When he speaks, I could almost see the wheels constantly turning in his head. His speech is clear and deliberate, much like that of a schoolteacher's.

Neurological and neuro-psychological examinations seem to be the central part of our visit. The staff looks for the earliest signs of the ALD onset to start the transplant. It appears that the disease diagnosis alone is not sufficient for them. Although our son appears to be normal neurologically and has done OK in school, Dr. Shapiro thinks that he has changed for the worse since the Kennedy Krieger report seven months ago. Dr. Peters uses that assessment to recommend the transplant.

On the support side, a social worker will be assigned to Kyle, Sue and me to help us cope with the stress. In addition, a local family can be arranged to be our care partners. The Minneapolis School System will provide a tutor to teach Kyle both in the hospital and at the Ronald McDonald House (RMH).

Visiting Twin Cities' RMH is the last thing on our agenda. We find it with ease. It is only two

and a half blocks away from the Fairview-University Hospital. The complex has two buildings, stretching from Oak Street to Ontario, separated by an alley. Units within range from rooms to some apartments complete with a kitchen. There is a laundry on every floor. The whole facility is designed and equipped for a long family stay. It has two game rooms, an exercise hall, a computer room and a phone closet for free long distance calls, not to mention a book and a video library. You might say it is like a self-service Ritz. Thoroughly impressed, we leave Minneapolis with only one unsettled question: is there a Waldo of a donor out there in the sea of humanity? It should be easier this time because Minnesota only needs a 5-of-6-antigen match.

## ***8 -- Precious Little Time***

It does not take long for the business manager, William Taborn, to secure the insurance coverage from Selectcare, our HMO provider. At the same time, he is able to convince them to cover the donor search as well.

As the summer passes, time becomes more precious for me. Doing things with my son takes on priority. I try to take as many pictures as possible. One by one, we fish all the lakes around Brighton. Shooting the basketball and practicing soccer become daily events.

The search by Minnesota appears slow. I suppose my higher expectation is a part of the reason. However, from my conversations with Tim Krepski, the donor search coordinator, I get the feeling that NMDP has been trying to contact a person since mid-July. In August I get the word that the target donor is having her HLA's re-tested. The antigen match is a 5-of-6, good enough for Minnesota. Unlike the first time, I have only revealed the search status to a few people for fear of another disappointment.

I suggest to Kyle that we should try Salmon fishing from the Ludington Pier on Lake Michigan over the Labor Day weekend. The season is still too early but it is worth a try. We have never gone fishing that far away, let alone in a Great Lake. I want to chalk up another memorable experience. As if pushed by an irresistible force, we blitz to Manistee, another place on Lake Michigan on the third day before returning home.

Wes Szpunar has been going to his cottage every other weekend this year. I have not seen his retreat on Lake Huron's Alpena Bay since its purchase 4 years ago. Thinking perhaps to get away for the last time, I offer to drive on his next trip. Nestled in the trees is this petite yellow and red three-room hideaway. The beach is covered with pebbles whose size ranges from that of a golf ball to a grapefruit. It is a gold mine for a rock hunter like my boy. Down the road lives Wes' sister Helen. She has a boat pier on her property. Knowing what Kyle is about to face, she has asked her friend and neighbor Ed to pick him up from the pier to go fishing in the Bay--what a thoughtful gesture.

A phone call in mid-September from Tim Krepski puts a stop to our hectic weekend forays. He tells me that the donor is all confirmed and ready to donate. She can do it any day, which makes me think perhaps she is a full time mother. I am excited and nervous at the same time.

“When do you want to come to Minnesota?” asks Tim.

“Let me see... Is there a referred day for us to come?” I try to hide my anxiousness.

“Mondays seem to be the most common,” Tim suggests.

Flushed with excitement, I propose, “How about Monday, September 21? Before I commit to that, I’d want to check with my wife.”

“That sounds good. The pre-transplant work-up should take about a week. We will firm up the marrow harvesting date and determine the admission when you are here.”

The waiting is finally over. I call Sue right away to check the date for formality. She agrees fully that Kyle should go as soon as possible.

When I return home that day, I call Kyle back into the house from outside. Upon hearing the news, he stomps away. Son, I am sorry. It won’t be easy. Yes, you will suffer tremendously. Yes, it will be difficult for your sisters. And, I know it will be draining on your mother and me. We just have to do it.

The news spreads quickly. People in schools, stores, churches, bowling and golf leagues, banks, newspaper publishing, radio station and our neighborhood are excited for us. The offer to help and to pray seems to come from everyone I run into. At the same time, time-occupying gifts and well-wishing mementos start to pour in for Kyle. Joyce and Shila have not been idle either. They together have compiled a list of more than 30 mothers who have expressed their willingness to give them rides. Mrs. Asher though is their favorite. Unbeknownst to me, the women close to Sue have also planned to provide meals on a regular basis for the girls and me in the coming months.

Our church suggests that we go up to the pulpit to announce Kyle’s impending departure. The congregation is familiar with his need to find a donor, and many hundreds have given generously to his Trust Fund. But this is the real thing – a matter of life and death. Even if he survives, what kind of life might he lead? How much suffering can he endure and for how long? How might he handle the long isolation? How will I react to all that? Surrounded by Sue, Kyle and the church elders, I announce the details of what we will soon face as a family and ask for God’s mercy.

## ***9 - One Way or Round Trip?***

My son and I are about to make the fateful trip. A lone small hard case Samsonite is standing in our foyer. It contains all the clothing for Kyle. Lying on top is Digby the stuffed dog, his sleeping companion for the past few years. Suddenly, I see the reason why Kyle has such an affinity for it: it strikes a resting pose that says “Please join me”. Somewhere in the suitcase is a photo album of the people and pets that are close and dear. Does the trip boils down to just a pack of clothes and

memories? No, I won't let it. To me it captures all the emotions that have plucked every fiber of my being. It might as well be ten over-stuffed suitcases, full of anguish, ready to burst on a slightest trigger. "God, make this a round trip for my son!" I beg out loud. I can almost hear the echoes of my voice. But there is no answer, just silence.

The medical experts have put Kyle's chances at 70 percent. They may be OK for someone else but not for the person who is my son. If there were a way to improve on them, I would pursue it. Then I am reminded that I have done every thing humanly possible.

I asked Sue the night before not to wake up to see us off. But I wonder if she can really sleep through this first step of our 650-mile journey. After a silent prayer, I back the van out of the garage. In the darkness of the morning, and alone with Kyle, the weight of my son's life sits squarely on my shoulders. I have to fight back tears as I put the transmission into "Drive".

The headlights from the van push the darkness back on U.S. 23. The lines on the highway seem to want to hug me and tell me that there is no turning back. I am passing Whitmore Lake as the radio plays that Oldie "Rhythm of the Rain" by The Cascades.

*"Listen to the rhythm of the falling rain, telling me just what a fool I've been.  
I wish that it would go and let me cry in vain, and let me be alone again.  
Now the only girl I've ever loved has gone away. Looking for a brand new start!  
But little does she know that when she left that day. Along with her she took my heart.*

*Rain, please tell me, how does that seem fair..."*

The notion that a steady rhythm could evoke a lament overwhelms me as I hear the hum of the road. My forehead and eyes begin to swell. I hope I am not a fool by taking my son away to look for a brand new start. I just hope and pray that he does not take my heart...

The darkness begins to fade. There is now enough light for Kyle to take out his Game Boy to play. In fact, the lure of the new game given by Chrysler employees has kept him awake all this time. Its irregular beeps now pierce the steady road rumble. One might even say that it is somewhat musical. I realize that what used to annoy me now becomes quite tolerable.

We are near the Indiana border now. Ahead of us is a truck pulling a trailer full of hogs. I joke to Kyle about what these creatures are about to face. Through the holes I can see them huddle together, bouncing with the trailer. Their blank faces tell me that they haven't got the slightest clue about what lies ahead. As I pass the truck driver, I turn my head to take a peek at him. At that precise moment it dawns on me that what he is doing is not much different from me. Will my return trip be empty just like his? Oh, I can't bear the thought. All I want to do is pass him and never look back.

The week before the hospital admission is filled with consultations, tests and re-tests, trial runs and classes. I try to fill the free time with as many activities as possible. We manage to take advantage of a couple of free tickets to see a Twins baseball game at the Metrodome. In

everything we do though, the feeling of the *Last Supper* seems to haunt me.

As the admission day nears, Kyle and I have re-discovered the joy of shooting basketball. His reason is quite different from mine. I have been encouraging him to shoot and dribble with his left hand since the beginning of the summer. A bounty of \$2 has been offered for each basket he makes. He has only made it once before. Without homework and playmates, he now shows renewed interest to try it again. Within one session, he makes \$10. This calls for a change in my offer. I lower it to \$1 a basket, then again to 50 cents. Finally, after three days, it is down to a nickel with a left-hand dribble. This should give him something to relish in the difficult months ahead.

The Game Room in the basement of the Ronald McDonald House turns out to be Kyle's candy store. Trying to bring him up for meals and to bed is nearly impossible. In the mean time, we have found a new competition: the race to our room on the 3rd floor. I'd go by the elevator while he runs up the stairs. He always beats me though. Little does he know that these exercises will help him face the long battle ahead.

It is Friday morning, our wrap-up day at the Bone Marrow Transplant Clinic. Sitting with us in a small private office on the 5th floor of the Phillips Wangensteen Building is Dr. Peters. The purpose is to review the procedure, the possible side effects of all the drugs and the risks during the recovery. To my chagrin, almost all drugs individually could result in an organ damage: if it is not the liver, it is the kidneys, the lungs, the bones or something else. I am so disturbed that I ask what the combined risk is. The answer comes back around 15 to 20%.

"Here is the consent form. I am asking you to sign as Kyle's father," says Dr. Peters.

I pause for a brief moment then mumble to myself, "If this does not work out, I'd be signing my own son's death warrant or sentencing him to life long suffering!"

"Dr. Peters, let me ask you one last question," I proceed to finish it after a deep breath, "If Kyle were your son, would you go ahead knowing that he is OK now?"

Dr. Peters pauses for a moment. Then he gives me an answer that I'd expect more from a lawyer than a doctor. What I desperately want to hear from him is his anguish, his empathy and his fear from the deepest part of his soul. How could he? Kyle is not his child. His job is to give me the best standard opinion. The simple truth is that my question just cannot be answered adequately by anyone else.

"God, are you with me?" I ask silently. Not wanting to prolong the agony, I pick up the pen and quickly sign the form. Thus begins race to beat the 30%.

## ***10 - Greeting Card Shower***

The Oil and the low fat diet are suspended on Tuesday, the day before Kyle's admission. This is the first day in nine months that Kyle is free from any restriction. And yet, I can definitely sense

the hesitation in him for making an unrestrained meal selection.

The message on the answering machine confirms the time we should check in at Surgery. We are to arrive at 5:30 AM for the first procedure scheduled for 7:00 AM. Four operations are to be performed on that day: Hickman Tube implantation, a skin biopsy, a spinal tap and bone marrow extraction. His own marrow will be used as a backup in the event of a mishap to the donor's.

Two days of chemotherapy using Cytoxan starts the next day, then followed by 4 days of total body irradiation, two sessions each day. The lungs and the brain are shielded by lead blocks cut to the shapes of the organs.

The combination of chemo and radiation makes Kyle very weak. Twice daily proton bombardments give me the chills. Out of nowhere, a seizure strikes during the 6<sup>th</sup> radiation session. Physicians rush to his side. After the recovery, he returns later to finish it. Oh, how I wish I could bear that burden for him. You are tough, my son. But you must be even tougher still.

The effects of the chemo and the radiation make him feel like having the flu with frequent nausea and diarrhea. His hair falls off completely, giving him a Michael Jordan look. Eating is suspended. He sucks on ice cubes to sooth his painful mouth and throat.

Before Sue's last working day, the ladies in the Brighton Food Services presented her with 30 presents for our son, one for each day of his recovery. This is the time to reveal their existence. Once known, the anticipation to get one becomes a daily highlight for him. The hospital's TV shows provide additional entertainment for the young patients. Kyle looks forward to playing the TV Bingo games on Tuesdays and Thursdays. The prizes are later delivered to the winners in their rooms.

When the news of his extreme discomfort reaches our church, Pastor Alberta asks the entire congregation to send him cards. "I hope hundreds, perhaps a thousand would be sent to cheer him up", he urges from the pulpit in all three services on Sunday morning.

On that same weekend, his white cells start to come in, doubling and tripling every day. In the mean time, the cards are arriving in droves. The walls in Room 18 of Unit 4B are covered with them. Kyle gets tired just from opening them. Many send money and gifts as well. His misery suddenly ceases.

## ***11 - Rendezvous in Rockford***

When we traded places last time three weeks ago, Sue and I met in Perkin's in Rockford, Illinois, the halfway point. Since it worked so well, we decide to do it again. Corned beef hash, two eggs, hash brown and pancakes are what I like. Although Sue does not have any favorite, she likes the variety the menu offers.

The bags are piled in the foyer, ready to go. I packed them the night before.

“Do I have everything?” I say to myself as I check all the pockets. “Oh, the battery for the Sony 8mm camcorder. It is still in the charger in the Study!”

I forgot the battery one time four years ago. I have been kicking myself ever since for missing the chance to video the Christmas Play in Hartland in which Shila starred.

I back the loaded Neon out of the garage into the darkness around 5:20 a.m. The garage door comes down like a stage curtain, breaking the light from the car. Yes, my time at home is over. After three weeks, Sue is coming home to be with Joyce and Shila. They have never been away from her this long. Sue is looking forward to taking Joyce to the hairdresser for the Brighton High Homecoming Dance while Shila welcomes a new driver for her newspaper delivery. All three need to rekindle that special mother-daughter bond.

Dash lines in the middle of west bound I-94 tick away the time toward Illinois. WWJ on the radio begins to fade in and out. I should either change the station or listen to a cassette tape. Against the darkness, glaring road signs and mileage markers pass me with a hypnotic cadence. Lights from the on-coming traffic stream toward me like an endless firing of night flares. Yes, I am still on the right course. At some point, I notice that the sky is not black anymore. A wavy horizontal line now splits the hazy screen in front of me. The landscape is becoming clearer and clearer. The road signs assure me that I am still on the right course as they repeat the name “Kalamazoo.”

“Sue must still be driving in the dark. I wonder where in Wisconsin she is,” my thoughts come to life. “She should be between Eau Claire and Tomah.” “I hope Sue will like her Sweetest Day present.”

“Welcome to Illinois”, the sign says as I enter into the Land of Lincoln. What we experienced crossing his land on our previous trips tells me otherwise. First, today is Friday, a workday. Thousands of truckers will be trying to finish their runs before the weekend. Besides, it’s 8 o’clock. Tens of thousands commuters are trying to get to work. I-94 is one of only two interstates linking the East Coast to Chicago. Second, I’ll now have to stick my left arm out from the Neon every 5 to 10 miles to throw 40 cents into the dreaded metal scoop. It would be my luck to miss one at the busiest booth.

Sure enough, it happens. Instead of the basket, a rogue coin hits the pavement. Panic sets in. Seconds now feel like minutes. I have to instantly choose between fumbling for another or go after the one that got away. I open the door to follow the rolling sound. The driver behind me honks to let the world know what a klutz I am. I feel like the whole world is staring at me. The coin that causes me the embarrassment is spotted. Good, it is within reach. I would pick it up even in sludge. With my hand safely in the basket, I let go of the renegade. The green light comes

on to replace the red. Embarrassed, I take off like a racehorse with my head barely showing above the dash panel.

The much-feared traffic on I-94 shifts to I-290, just west of Chicago. The safety margin I have built up from Brighton starts to dwindle. Besides, the last of the three cups of coffee is adding to the pressure. The traffic finally clears when I reach the westbound I-90. My watch reads 9 o'clock. Now it's my bladder against the clock all the way to Rockford.

To my right, the Chrysler Belvidere Neon Plant comes into the full view. The next exit is where I get off. Since Sue has not paged me, I know that she is on time.

My eyes scan the parking lot as I pull into Perkin's. I immediately spot the lone red Dodge Ram window van. Because of its height, Sue can see me as well. I pull up next to it to exchange our luggage. Other than the clothes, Sue looks the same. We embrace and hold on to each other for a while. The green and yellow awnings of the restaurant disappear for a brief moment as I feel the pressure gushing up to my eyes.

Our breakfast is rushed since we both are still 5 or 6 hours from where we are going. And yet, there are so many things we need to tell each other. It ends up to be a one-hour breakfast meeting between a husband and a wife.

Reaching over the table, I place a small box tied with a gold ribbon in front of Sue. She looks surprised. It contains a heart-shaped gold pendant that I purchased at Twelve Oaks Mall a week ago. It was Sweetest Day then. The inscription says: *I Love You*. Somehow, it sounds hollow being a week late. But I want this piece to say what I cannot show her everyday. Now I can empathize a little with my parents for what they went through forty years ago. They were separated from each other for four years when my father came to the States to pursue his advanced degrees. People do what they must, just to pursue their goal, don't they?

My heart pounds to the rhythm of the walk to the hospital. Along the way, the gray squirrels tiptoe across the immense golden stage covered thick with fallen leaves. An occasional rustle seems to be the only sound that accompanies their performance. Above the stage, a gentle breeze consoles the few leaves still grasping onto the branches, as if to tell them it is OK to let go. The dancers suddenly freeze as I pass near, and then they scamper off in a new direction. I am approaching the street on which the hospital sits on. The 8-story red brick building with a chisel look rapidly comes into full view. My eyes aim toward the strip of dark glass on Kyle's floor, sweeping back and forth, trying to locate the exact window. My vision begins to blur as the emotions of the reunion fill my head. Is he all right by himself? Could he be watching TV or playing a game? Might he be reading? Has he touched the food? Does he truly realize how many people are praying for him? Does that mean anything to a ten-year old?

My heartbeat quickens as I small-step my way through the automatic revolving door. The stream of hospital employees rushing out makes me feel like an odd ball. I suppose we are all anxious to go from one routine to the next. Sue has warned me about how different Kyle looks now. As I walk past his specially filtered room to hang up my jacket and to wash my hands, a silhouette of a boy sitting up in bed flashes through the Venetian blinds trapped in the glass. Then I push down on the door handle. The click sounds unusually loud and deliberate. This is the moment that I have driven 11 hours for. Our eyes meet. I rush forward to hug him. "Stop!" I am restrained by a

firm voice from within, reminding me to avoid all physical contacts.

## ***12 - Emptying Out the Room***

As if a page is flipped, the view outside the window of Rm. 4218 takes on a new appearance--the trees have bared themselves to reveal the colonial look of the oldest dorm on campus, the Pioneer Hall. Clearly visible is the arch in the middle of the walnut color brick building. It leads into a courtyard. If one did not know any better, one might mistake it for an Ivy League structure. Against this seasonal backdrop, the life outside puts on its daily silent show for the hospital occupants.

Kyle's recovery is accelerating at an amazing speed. On the wall facing the foot of his electro-mechanical bed is a fresh poster. Kyle made it up one morning to cheer on the Michigan Wolverines in the upcoming football game with the Golden Gophers. Michigan State's unexpected loss at Minnesota a week ago was a disappointment. His spirit is back. In the last two weeks, only once did he have a fever. The doctors are talking about discharging him soon. Optimism builds with each of their visits.

I have already taken four bags of games, books, puzzles and get-well cards to our apartment. Except for the cards and the poster still on the wall, only the personal belongings are left. After a night's rest, I am returning to wait for the discharge instructions. Upon entering the room, I find Kyle in the middle of taking down the cards, re-reading each. What an emotional scene that is! It belongs in a movie. I am overwhelmed: a month of pain and isolation is ending with such a symbolic act. Hanging on the wall is a lone black on white calendar about the size of a text book. It displays the date of Oct. 30, 1998.

Behind the façade of excitement lies a fragile new life. My son will soon test the harsh elements of the outside world. And, as for me, I am about to enter an unfamiliar territory as well. There is only one person of Kyle's age who is a post-transplant outpatient at the RMH. I have been watching Erin. Her recovery has been so smooth that she spends more time in the RMH School than the clinic. Is she an exception? Will my boy be as fortunate? Only time will tell. But for the moment, there is one reality: Kyle is leaving the hospital and I have to be ready.

## ***13 - Grandma Lib's Lesson***

It is now 5 p.m. The nurse in charge comes into the room to ask me to sign a bunch of forms. Then she hands me two pages of written oral and I.V. medications for me to manage. I don't know whether to laugh or cry. My experience to date has not gone beyond handing out pills and sticking on Band-Aids. I count 8 orals, 4 ointments, 3 IVs and a bottle of Hydrogen Peroxide. Their frequencies range from four times daily to twice a week. It would take a computer and a nursing staff to keep track of them all, and I am expected to do all that! She concludes by telling me that a home care nurse will come to the apartment this evening to teach me the I.V. and the

use of the pump. Then she hands me three or four different phone numbers that I can call later for help. I am numb beyond description.

“Others before me have done it,” I try to calm myself. “If it were so risky, they wouldn’t have asked me to do it,” so I rationalize to myself.

The home care nurse calls to confirm her teaching session with me. She is coming to the apartment at seven. Good, that way she can do the actual I.V. stuff while I watch and learn.

Her instructions fly across my face like a fast forwarding video, so it seems. I can only capture bits and pieces. When it is my turn to repeat, the nurse breaks out laughing.

“You have never held a syringe before have you?” she snickers.

“You mean a wrench is not close enough?” I retort.

“You should not dangle the bottle on top of the needle like that,” she points out.

“What is wrong with that? Marshmallows rarely fall off my stick when I go camping,” I try to be funny back.

“Again, this is how you install the tube to the pump...” “When the battery goes in correctly, it will make a funny sound like this...” “First, you get the air bubbles in the line out by dripping...” “To turn on the pump, you press the Start/Stop button until three bars show up...” There is no use: my head is still spinning, and my confidence simply refuses to rise.

I run into Grandma Lib in the communal kitchen. The time to cook and to eat is the opportunity for us to share each other’s information. She is from Raleigh-Durham in North Carolina. Her grandson Luke is having a complicated heart and lung procedure done. She watches her older grandson Mathew while her daughter Dana looks after Luke.

“How is Kyle?” she asks.

Wanting to tell her the good news, I reply, “I’m so excited that he was released from the hospital today.” “You know what they tell me though? They say that 90% of the bone marrow transplant patients will be readmitted”, I continue in a rather deflated voice.

She ponders a bit and then responds, “Oh, has it occurred to you that Kyle could be in that 10%. Someone has to, to make the statistic the way it is.”

That revelation jolts me like a lightening bolt! How many times have I scaled back my expectations because of the statistics. I wonder how different the world might be if everyone were to visualize oneself to be in that exceptional group!

Then we continue our conversation to recount the miracles that are happening around us.

“Do you know that man from South Dakota whose son is in the hospital for a brain tumor?” asks Grandma Lib, sounding as if she wants to tell me something new.

“Yes, I met Bob last time when I was here. I spoke with him yesterday to have learned that they had to put a shunt in his son’s brain,” I acknowledge the person she is referring to.

Eyes turning red, Grandma goes straight to the point, “When I mentioned how wonderfully these kids are doing last evening, he said to me, ‘there is no miracle for my son.’ Do you know that teenage boy is his only son?”

“No, I’m so sorry...” Oh, I want to cry out for that man. “Lord, why do you choose to heal some while not answering this man’s plea for his only child?” “Please answer me! Please answer him!”

## ***14 - Tao of Pooh, A Sermon***

Sue calls to tell me that Kyle was re-admitted into the hospital because of the blood in his urine. That ends our hope to be in that 10%. The medical staff concludes that the urinary track wall had ruptured--the result of not drinking enough fluids to flush out the chemicals. He is immediately put on the saline. Three days later he is released.

His outpatient status is not to last – our boy is back in again. The reason this time is the shortness of breath. Water has been filling up his lungs. Too much saline was prescribed. After an adjustment, he is out again.

As they gradually cut back the steroid Prednisone, Kyle’s cornea comes under attack by the new white cells from the donor causing it to nearly detach—a seldom seen phenomenon. He has temporarily lost his vision. The steroid dosage is immediately restored to the old level.

My son’s struggles are taking a toll on me. Losing his eyesight would make a bad situation much worse. It seems that my faith and all the prayers have not made a difference. Why wouldn’t God answer my sincerest prayers...how about those from others? All this anguish culminates in an unstoppable sob during the singing of Amazing Grace at the end of the Sunday worship service. ***“Amazing grace! How sweet the sound—that saved a wretch like me! I once was lost but now am found. Was blind but now I see...”*** The words “blind” and “see” are the trigger. My son could see but now is blind! The woman on my right hands me a tissue and begins to rub my back. As if pumped by the music and the lyrics, my sob becomes louder and louder when the singing reaches the 3<sup>rd</sup> verse: ***“...3. The Lord has promised good to me, His word my hope secures. He will my shield and portion be, as long as life endures. 4. Through many dangers, toils and snares, I have already come. ‘Tis grace hath brought me safe thus far, and grace will lead me home. 5. When we’ve been there a thousand years, bright shining as the sun. We’ve no less days to sing God’s praise than when we’d first begun.”*** I am still waiting for the promise to become true.

On my way out after the end of the service, I run into Kermit Morgan who is recovering from a major heart surgery. “How is Kyle?” he asks in a shaky voice. Eyes still red, I break down crying again. “He is having a rough time...” is all I can squeeze in before the next sob. He looks at me, teary eyed, and starts to wrap his arms around me...

It is against this backdrop that I am on my way to relieve Sue. Sitting on the passenger seat are two audio books from the Brighton Library. The one titled “The Tao of Pooh“ has intrigued me since I got it.

“Here is your chance”, I finally say to myself as the day breaks in western Michigan, hoping that I will not have to exercise my brains. It turns out to be just the opposite. I have to listen so carefully as to capture the interplay between the characters and the message. The author Benjamin Hoff cleverly utilizes Winnie-the-Pooh characters to teach the Chinese Tao (pronounced Dow) philosophy. I was exposed to it when I was young. It is like seeing a re-make of an old documentary – except this time it is in color with a new cast, a fresh commentator and a footage never before seen.

The Taoist teaches that we should always find a way to accomplish things by going with and taking advantage of the forces coming at us. Hoff uses the water and the rock to illustrate one of the Taoist central points. There are two ways water can get by a rock: pushing it out of the way or flowing around it. Since Taoism also preaches the principle of the least effort, the latter typifies the Taoist approach to life. Bingo! All of a sudden, I feel a tremendous relief throughout my whole body, as if a pressure valve had been opened up. In fact, for the first time since Kyle’s diagnosis, I feel at ease. I finally let go what I have no control of.

It dawns on me that I have been so wrapped up in selfish prayers for my son that the element of *trust* has been totally ignored. I have completely overlooked God’s plan, timetable and method.

Sue has not seen the new leased minivan. She was intrigued by the new Silver Fern color to have picked it last September. Joyce and Shila are elated about what the captain’s chairs offer them: individual space, which means no more fights. I wonder how many conflicts these chairs could have prevented on our school buses.

When I enter the apartment, I have to dodge all the bags and boxes that have taken over the floor. She wants to take them back to Brighton. I imagine that we have to do that again since the cards and gifts just keep coming.

Kyle’s eyesight is rapidly improving. But Sue has had to fight him to apply a lubricant and antibiotic drops to his painful eyes. I feel fortunate since my three stints in Minneapolis have been easy. Knock on wood.

The Dodge minivan is shown to Sue. She looks it over and gives me her approval. It drove flawlessly on my trip here. I just know that she is going to enjoy driving it back.

My parents and brother will join me in Minneapolis from California this time. I had told them that the better time to come would be when he is out of the hospital. It would be their first Thanksgiving spent with Kyle--ever.

My parents are the first to arrive. They have ignored my weather reports and are surprised by the warm November temperatures. It does not look like they will ever need to wear the heavy thermal gear that they brought. Having been primed, they are not overly shocked by Kyle's appearance. Once inside the apartment, they begin immediately to pull out the goodies. Kyle is all smiles when he sees his favorite snack: Chinese beef jerky. It comes in many different flavors and textures: fruit, curry, red pepper, moist, dry, etc. His grin is barely detectable on his puffy face. The gap of two thousand miles is instantly closed with this treat. Can this be another Taoist lesson?

My brother Jim is a resourceful guy. Not only did he locate the nearest hotel to RMH, the Radisson on Washington St., but also secured the lowest room rate through the Internet, so he tells me. He arrives the morning after Thanksgiving, having just taken a red-eye express from San Jose. No sooner does he enter the room than he proceeds to pull out his goodies from a large bag. The radio control Jeep Wrangler gets Kyle's immediate attention, followed by a few Beanie Babies.

Kyle's exposure is limited to no more than 10 people. Newly united, we decide to drive around to find a suitable place for dinner. The first restaurant we try on campus is too full for his safety. Anticipating that the crowd would be a problem at the university, we decide to drive farther out to find a suitable one. Leann Chin's on University Ave. in St. Paul looks pretty empty through its front glass. We agree to give it a try. As the driver, I am the first to get out of the car. Trailing behind is a slower Kyle, then followed by my brother and my parents.

"I fell," Kyle screams suddenly.

Turning around, I find him kneeling on the concrete, about to cry. We all rush to grab his arms to help him get up. Although in pain, he refuses the help in his usual stubborn manner. It is apparent how much weaker he has become. We are all taken back by his collapse. They are puzzled by his adamant refusal for help while I am fearful of the possibility that his ALD is still progressing. I ask Jim if Kyle lost balance or his knees simply gave out. Jim's answer indicates that it is the latter. My fear is eased somewhat. Still, we can't seem to shake the incident throughout the meal. I have to remind myself of my new attitude to trust and let go.

## ***15 - Family Stress***

"Hi, it is me," I phone Sue to give her an update, "We went to HarMar Mall yesterday. My parents wanted to buy him the Beanie Babies that he did not have. I used the wheelchair and the mall was not too crowded. The prices there are really good..."

“I think you are really pushing it. If he gets sick, guess who will have to spend more time with him? You have taken Kyle to too many places. Don’t forget: he is weaker than he looks,” Sue sounds angry.

“But how was I supposed to know what the shop carries that he does not have?” I answer back.

“You could have waited...” “Click,” she hangs up the phone.

I am caught between wanting to satisfy Kyle and my parents and keeping the guard up. I know she is furious. She probably won’t speak with me for a week. When I mention it to my parents, they feel a bit guilty. But I know they have experienced similar spats in their long relationship. Only time will cool her down. There is nothing further I can do.

As the week progresses, my parent’s attention shifts from their grandson to the life at the RMH. The morning is hectic because of the extensive medical and personal care rituals, not to mention the “getting dressed” part, which seems to take forever. They try to stay out of the way. Then we will not return from the clinic until the afternoon. Since Jim has a car, they start to venture out more and more during the day: the first is the Mississippi River, then Mall of American, St Paul’s Cathedral, Billy Graham’s Crusade...

Throughout the week, volunteer groups are scheduled to prepare dinners at the RMH. Because of Thanksgiving, the meals are more elaborate this week. Tuesday night is kids’ activity night where a volunteer teaches craft-making. Bingo games on Wednesday night are the highlight of the week for both adults and children. In many ways, the life style resembles that of a camp, minus the rigidity. By virtue of the its communal living, the RMH is a place of constant emotional support and information. It is ironic that I find security in hearing and seeing others grapple with the uncertainties of life.

Jim and I want to have some time alone. It is around 1:30 in the afternoon already. My boy is all set until dinner. Nicolette Street is known for its international restaurants and shops. Jim, by driving around in the last few days, knows where it is. The presence of the immigrants from Vietnam is everywhere in Twin Cities. Nicolette is no exception. We come upon a German restaurant however. It has been twenty some years since Jim worked in Germany. He has many fond memories of the country. For a change, we decide to have a German meal complete with a German beer. He still remembers some of the menu items and delights in telling me what they are. Our conversations cover a wide variety, some dating back to our childhood. The time capsule seems to end only too quickly as the rush hour traffic begins. We don’t intend to be caught in it.

Over the years, my parents have really grown inseparably close. I don’t know how one would survive without the other now. It is especially heart-warming to see that they still can travel, staying independent. At least, they are near Jim and his family--a relationship my family has never experienced. I guess I will always wonder about that.

Sue arrives to relieve me on the day my parents take off for California. I am going back the next

day. After a hug at the back entrance where she comes in, Sue asks me to unload her luggage while she makes a call to see if Joyce is home with Shila. She has asked that because there would be no supervision back at our house.

Sue is steaming--Joyce is not there.

“She is grounded for two weeks. I was lied to. She promised me she would be home. I can’t trust her even for a day,” Sue vents her feelings out loud.

Sharing her indignation, I follow up by saying, “You do what is right. Just tell me when the grounding is over so I can enforce it.”

Sue proceeds to track Joyce down by calling a few possible places. In the mean time, my parents are wondering what might be going on—whether Sue is still angry with me. But when I tell them what Joyce has pulled, they understand fully what we are trying to do. I can only hope that their flight back would be totally stress-free.

## ***16 – Bad News In and Out of the Trenches***

For two weeks at home, I have played the role of the enforcer. Without Sue and Kyle, we hardly feel like preparing for Christmas by ourselves. Suddenly, the unusually warm fall weather takes a dive. 50 and 60-degree daytime temperatures surrender to single digit readings. As I head back to Minnesota, a thin veil of snow now drapes over the rolling rural Wisconsin landscape. Poking through are patches of trees and an occasional farmhouse. Two dark strips of Interstate I-94 split the wintry scene into uneven halves. The air is cool, and the day is short.

The bunched up exits on I-94 before the St Croix River tell me that I am near Minnesota. The shape of my second home state reminds me of a bloated “K” donning a tiny hat. A welcoming sign cut to that shape stands tall on the way to St. Paul where Jesse “the Body” Ventura will soon reside. I did catch a debate among the three gubernatorial candidates last fall. His no-non-sense attitude is a breath of fresh air. The downtown skyscrapers and the St. Paul Cathedral signal the end of my long trip. I feel rejuvenated. Huron Street exit beyond the city limit is where I get off. The RMH is just a few blocks from there. Pulling into the alley from Fulton Street, I notice the added Christmas lights strung on both buildings. Kyle’s recovery has been uneventful since his eye episode more than a month ago. According to Sue, however, he has been sleeping for much of the day recently.

The picture of Santa now decorates the outside of our apartment door. The motif has undergone several changes since Halloween. I enter the room after a short knock. My boy is resting in bed while Sue comes to greet me. He looks like a stuffed stocking doll with a contorted face. Prednisone is the cause. One can easily mistake the black Herpes scab in his left nostril as an accidental paint drop on that doll’s face. Before I am fully situated, both are eager to show me the things recently acquired. RMH is giving each family a gift everyday for the twelve days before Christmas. Kyle shows me the large Holiday cookie he decorated last Tuesday night. Then, Sue

leads me to the new fleece coat in the closet, which is supposed to be my Christmas present for her. Piled high on the table and on top of the refrigerator are cookies, brownies, gingerbread house pieces and candy. One might say the scene looks like Cornucopia a la RMH.

“I have moved the goodies in our kitchen cupboard to the top shelf because a kid has been spotted stealing,” Sue informs me and continues, “I’ve been locking the apartment door too, just so you know.”

I shake my head to show my disgust, and then I quickly acknowledge that I’ll do the same. Then Sue points to the medication poster chart taped to the wall by the spiral staircase. There have been several small changes.

“He had a four-hour nose bleed the night before. I finally had to tape his nose shut after using up two boxes of tissue. I was debating whether to take him to Emergency, but it finally stopped. The blood got on the pillow, the sheets and the cover. I washed three loads earlier today, and I’m going to need the sleep tonight,” Sue continues to fill me in.

The shift change has become routine. This time, Kyle and I will spend Christmas in Minneapolis while Sue is home with our daughters. They will then join us for Kyle’s birthday and the New Year’s. Except for a few families, I have missed the news from the rest.

I run into Cindy in the kitchen just as she is going out to her car.

“How is Jonny doing?” I ask.

“Oh, hi! He was readmitted sometime ago because of a fever. They found a few fungal infections,” Cindy answers. “It has been three weeks, and he is still not over them. Jonny wants me in the hospital room everyday. So I have spent a lot of time there,” she goes on saying.

“That is too bad. He had been everyone’s benchmark the last time when I was here,” I sound disappointed.

“I know. I was hoping to take him home early. I guess that is why they say it will take 100 days,” Cindy agrees in a similar voice. Wanting to share my newfound attitude, I then add, “I have changed, you know. I just take things as they come. I’m not optimistic or pessimistic. I just do the best in the situation.”

It is about 3 in the afternoon. Kyle is taking a nap. I hear a knock on our unit 9 door. It is grandma Post from the room across the hall.

“We almost lost Liat this morning,” she says without a greeting.

“What happened?” I ask as she leads me to her room.

“Both her liver and her kidneys had shut down. I knew she did not have a chance when Liat’s

leukemia turned acute this past summer. My daughter-in-law, who is a doctor, told me so. But we have to try the transplant as a last resort. You know my granddaughter is a talented, beautiful girl. She plays the violin and the piano. She is chosen as the first chair in the band. She also writes poetry. Why does God always want to take the fairest?... You know, there is book by Rabbi Kushner titled: *Why Do Bad Things Happen To Good People*. Maybe the Messiah will come to save this child..." grandma Post bares her painful soul to me in a soliloquy. My eyes turn red, and all I can mutter is a sigh.

After the lengthy evening routine of oral medicine, I.V. injection, dressing change, personal hygiene, eye medication and eye drops, I pick up the phone to call Buffalo, N.Y.

"Hello, is this Sheila?" I inquire.

"Yes," a tentative voice answers.

"This is Leonard Wu, calling from Ronald McDonald House in Minneapolis. Many people here want to know how Jimmy is doing after he was sent back. I volunteered to call you," I continue.

"Oh, hi. How are you? Jimmy is getting a Tracheotomy in the Children's Hospital. After that, he will be taken to a hospice," Sheila says in a calm voice.

I feel my inside separate and sink to my feet. I cry out silently, "God, can you do something?"

"How is Kyle? My older son Steven and I pray for him every night," Sheila quickly changes the conversation.

Feeling somewhat awkward, I reply, "His recovery is on schedule, and he is doing well." At that moment, my vision turns blurry. Sheila had hoped that her Jimmy would follow Kyle's progress. "How is Jonny doing... How about Laramie...and that Dean boy?" Sheila goes on asking about the others.

Six-year old Jimmy was hurried to Minnesota for a BMT in November because his ALD had been progressing rapidly. Jimmy's battle has captured the heart of Les Osenkowski, a Chrysler colleague. As a sign of hope and devotion, he sent Jimmy a swatch dipped in the oil that came from the Miraculous Weeping Icon displayed in a Greek Orthodox Church in Livonia, Michigan. After the transplant, Jimmy's condition took a turn for the worst. There was nothing further Minnesota could do. I can only imagine what the Schmitts have gone through trying to save their Jimmy.

## ***17 – Year End Reunion and Birthday***

Lasix makes Kyle get up often at night. Tonight is different though: he does not seem to want to go back to sleep even after my urging. In my grogginess, it comes to me that this is the night before Christmas. Kids are supposed to have anticipation and anxiety attacks. That boy wakes me

up at 6 o'clock, and he is determined to get me out of the bed. I finally get up and mosey toward the door. When I swing it open, a brightly colored 30-gallon plastic bag blocks the doorway, and there are others dotting the hall as well. This is the moment for which my boy has been staying awake!

"I heard that Pete Carlson has arranged a limousine to take your whole family to see the Christmas lights around the city. When is it again?" Pat Kasell asks when I run into her in the clinic. She is the director of the Care Partners at Fairview.

"The 28<sup>th</sup>. Isn't that wonderful? It will be the first time we are together since last September. You know Kyle's birthday is Dec. 30," I answer excitedly.

Pat follows up in a creative way, "You know what else I like to do? I am going to ask Channel 5 to do a news piece for this event. Is that all right with you? I also think it would give some publicity to the limousine company."

"It sounds great. I'll tell my family to expect the news crew."

I call Sue in Michigan to tell her about the added program to the original Christmas Light tour. Instead of showing excitement, she sounds rather preoccupied, "I might take the girls with me to go down to Kentucky before we swing up to Minneapolis. My cousin Ruth called to tell me that Mamaw is in the hospital again. She is not eating."

"That is a lot of driving. Do you think your Alzheimer's mother will know you?" I question her logic.

"I am doing it for me. I might feel guilty later for not seeing her alive one more time, but I'll talk to Ruth before I decide", Sue answers back.

I am so ashamed for missing her feelings. I know I'd feel the same in the same situation.

I have been restless since getting back from the morning clinic. I keep looking down at the parking lot from our 3<sup>rd</sup> floor window. "They are here," I shout out to Kyle when I spot the Silver Fern minivan. His face shows an instant relief as well. It is almost 4 o'clock, and they have less than an hour before the television crew arrives.

Sure enough, Chris Paltrow of KSTP and her camerawoman show up at the RMH entrance at 4:45. There is still light outside. After the greetings, she lays out the plan for the evening: first, the interview with our family, followed by another interview with our care partner Pete Carlson, and then the two-hour limousine ride. Chris is determined to see the inside of our apartment. Against Sue's wishes and without her knowledge, she manages to persuade me to let her in for a quick look.

The inside of the limousine is like an adventure. As we each pick our spot to sit, the excitement of discovery quickly overtakes us. I am torn between eating and looking at all the features inside.

Waiting for us are a platter of shrimp, grapes, cheese and crackers and a pot of Buffalo wings kept warm by chemical heat. Two bottles of sparkling juice sit in the rack. But the first item the kids reach for is a box of Bugles. With the camera rolling, Chris Paltrow squeezes into the limousine to capture our initial reactions and ask us more questions.

Silly giggles from the children provide a constant backdrop to the family chitchat. After all, they have not been together for three months. It is obvious that they have missed one another terribly. As the limousine weaves its way into the neighborhoods, our attention is drawn to the awesome Christmas displays. OOO's and AAH's stream steadily out from our mouths. I can't imagine the electricity bills these families will have to pay. All the while, the camerawoman in the front seat keeps shooting more footage for the telecast later.

"I saw you and your family on Channel 5 last night," shouts one of the nurses at the Clinic. "Yes, they did a story on us," I acknowledge her as I wheel my boy into the room for his daily checkup.

Then I continue, "I'm leaving on the 1st to go back to Michigan. My wife will stay with Kyle. The 100-day milestone is coming up. I don't plan to be back." It is time to say good-bye to the staff who has become a family to me. Whether it is Thanksgiving or Christmas, Saturday or Sunday, they are always there. When Kyle is grouchy, they remain cheerful; when he is uncomfortable, they recline the couch for him; when he is weak, they tie his shoes; and when he needs to swallow the pills, they bring him drink. Oh yes, I will sorely miss them. The passage from Ecclesiastes says, "There is time for everything, and a season for every activity under the heaven: a time to be born and a time to die,...a time to plant and a time to uproot,...a time to weep and a time to laugh,...a time to embrace and a time to refrain,...a time to tear and a time to mend,...a time to love and a time to hate,..."

Because of his birthday being so close to Christmas, we have always chosen to celebrate it a month later. By then, our son should be home. The convergence of the two would really be something. Besides, our boy has seen so many gifts to last him a lifetime. For the moment, we are all together for this life's milestone--isn't that the real celebration?

## ***18 - Messages in Christmas Cards***

The reunion has been short. The night before, we went to the Rossbachs and the Pavliks on the third floor of the Ontario Street RMH to celebrate the New Year. Casting aside future worries, members of the three households talked, shared and laughed as if life had been normal again. Gary Rossbach is an American Airlines pilot with a special gift of caring. He sends Kyle post cards from the places he flies to. Gary, his wife Kim, Sue and I have a special bond in that we both adopted a son from the Orient. Zak and Kyle are the same age and going through the transplant at the same time--another life's coincidence.

I have to take the girls back to Michigan because Joyce has a varsity wrestling meet on Jan. 2. She is a trainer for the Brighton team while Shila has two newspaper routes. The Neon is stuffed full of gifts, coats and luggage. I am bringing back all my personal belongings since Kyle is

scheduled to return home on Jan. 25. The threat of a major snowstorm adds to the urgency to travel fast on New Year's Day.

Without any Christmas lights our house looks dead by comparison. I pull up onto our driveway in the dusk. After we unload the car, I enter the study to start reading the letters and Christmas cards, which have been piled on my desk. There are many from well-wishers whom we don't even know. Paper cuts or not, I am determined to tear open the envelopes as fast as I can. Messages of encouragement parade across my eyes like a ticker tape. Here is a sampling:

A special note from Bob and Rosemary of Ford Motor Company ends this way:

***"...Please accept these gifts from our hearts to you at this time, including this ½ gram of saffron, the world's most expensive spice. East Indians give it as gifts for luck to their loved ones. I grow this saffron in my back yard and offer it to you as a symbolic gesture for the best in the future."***

A card from our next door neighbor Ray, when we lived in Livonia, says:

***"Say to those whose hearts are frightened: Be strong, fear not! Here is your God. He comes with vindication; with divine recompense he comes to save you... Those whom the Lord has ransomed will return and enter Zion singing, crowned with everlasting joy; they will meet with joy and gladness, sorrow and mourning will flee." Isaiah 35:4,10***

Yakels of Brighton sent one that contains this quote:

***"Now faith is the substance of things hoped for, the evidence of things not seen." Hebrews 2:1***

A story in the card from the Lisonbys goes like this:

***"One night a man had a dream, and in it he reviewed the footsteps he had taken in his life. He looked and noticed that all over the mountains and difficult places that he had traveled there was one set of foot prints... but over the plains and down the hills, there were two sets of footprints, as if someone had walked by his side. He turned to Christ and said, "There is something I don't understand. Why is it that down the hills and over the smooth and easy places you have walked by my side; but, here over the tough and difficult places I have walked alone, for I see in those areas there is just one set of footprints." Christ turned to the man and said, "It is that while was easy I walked along your side; but here where the walking was hard and paths were difficult, was the time you needed Me the most, and that is why I carried you."***

Tom of Cary, North Carolina, writes:

***"... Say hello to Kyle for me. ...Tell him that Uncle Tom fell off the ladder last Oct. and shattered his patella. But he would not give up. He is a fighter. He is determined to go through all the physical therapy (PT, which stands for pain and torture) that the doctor has ordered. He screamed and cried... and he scared the heck out of a 10-year old boy next to his bed in the PT room... I don't pray much. But this time I will for Kyle. I hope he can get back on his feet again soon. Run, laugh and dream like a boy again..."***

These Christmas messages keep percolating in head. They would pop up unexpectedly as if triggered by an invisible timer. Oh, the power of words!

## ***19 - The Bottom Falls Out***

Since I came back, the phone calls from Sue have continued to suggest that she will bring our son home on schedule. The good news is spread to his school, our church and people at work. I have even mentioned to my boss that I am ready to take on additional responsibilities.

What appears to be certain takes an ugly turn -- Kyle is back in the hospital due to a high fever. Spots are visible on his chest X-rays. The doctors right away assume that they are fungal infections. He is on seven or eight antibiotics. They expect a 10-day stay this time. There is still a small chance in my mind that Kyle may return home on schedule.

I am leafing through the Saturday Argus. An article about a fund drive for Josiah Claypool gets my attention. His bone cancer has spread to his lungs. It sounds utterly serious. A year ago, this young boy lost a leg to Osteogenic Sarcoma. Now the Claypools are desperate and have chosen a very expensive alternative treatment in Mexico. Prompted by my new resolve to help other children in dire medical needs, I decide to show up before the auction at Hartland High School.

“I am looking for the Claypools,” I ask the person standing at the auction entrance.

“Let me see...There he is. See that man next to the donation table? He is the father.”

“I am Leonard Wu. I have something to donate. I am Kyle’s father.”

“Oh yes, I have read about your story. I am Bob, Jo’s father,” the man replies as he shakes my hand warmly.

Then Bob proceeds to tell me the rest, “Jo is coming in a wheelchair shortly. His mother is bringing him. Several months ago, at the State Fair, he climbed a rock wall with his artificial leg. It was on the TV news. That was before the spread of the cancer. The doctor at U of M was optimistic when he was first diagnosed. He thought it was caught in time...”

While still talking, a boy is pushed toward us in a wheelchair by a woman. Another lady, who obviously is someone close, goes forward to greet him in tears. Unaffected, the blond boy looks straight at me. He is thin but alert.

“Honey and Jo, this is Mr. Wu, Kyle’s father,” Bob starts to introduce me, “Mr. Wu is going to donate....”

“Ssshhh,” I cross my lips with my index finger, “It is confidential.”

Then I step forward to shake the mother’s and Jo’s hands and say in a proud voice, “Jo, you are a

specially brave boy. Your father told me about that rock climbing you did...I am going to tell Kyle all about you.”

As Jo moves on to meet others, Bob’s eyes and mine meet in such a way that we both turn our backs to the crowd and start to sob. No words can explain it. Only those who are trying to save their own child would understand.

The bad news keeps coming. Pneumatosis is found in a section of Kyle’s small intestines. Dr. Davies says it could be an infection or the result of the radiation or the chemo. The Herpes Simplex virus and VRE bacteria discovered in his nose have gotten into his blood stream. Kyle’s stay in Minneapolis is extended by two more months.

The news deflates me and those around me like a pricked balloon. Four months is long enough for anyone to stay vigilant. Imagine two more! Who knows, it could even be longer! This unexpected development is tantamount to moving the finish of a marathon down another 13 miles!

Kyle’s fever refuses to go down even after ten days, and the nodules in his left lung have grown in size. Biopsy of the lung and the sinus cavity are performed. He is put on the ventilator to help him breathe deeper after the procedures. A drainage tube is inserted in his chest. They have to sedate that poor boy to keep him from pulling on the mask. But he is determined to take that restriction off whenever the sedation begins to wear off.

The lung biopsy reveals the Epstein Bar Virus Lymphoma where the B cells congregate to fight the Mononucleosis Virus, but he does not have enough T cells to control B’s multiplication. To increase the T cells, Dr. Davies stops the immune suppressant CSA and increases the Prednisone. In the mean time we all hope that the Graft vs. the Host Disease (GVHD) does not flare up.

Over the phone Sue reminds me of Joyce’s upcoming big event: “Next Saturday is the Winterfest at the high school. You’ll have to take her to the hairdresser and then the florist. She and her circle of friends will meet at a house before they go to the dance. Make sure you take pictures so that I know how she looks.”

“Do you want me to take video too?” I ask.

“You know you left your camcorder at the RMH? You’ll have to borrow one.”

“Is Joyce going with Jason?” I probe further.

“Yes.”

Saturday comes quickly. It takes all afternoon for her to be ready for the dance. Joyce informs me that Danielle’s dad will loan me his video camera. I can pick it up when I drive the two young ladies to the congregating house.

At 5 o'clock, Joyce comes down from her room, carrying a short silver dress that would bare her shoulders.

“What happened to the long black dress you and mom picked out in Minneapolis? You will be cold in that! Does mom know about this?” I disapprovingly ask.

All she is willing to say is, “I want to wear this one. I will wear the other to the Prom.”

“Dad, try not to be funny or you will embarrass me. OK?” Joyce pleads, wanting to change the subject.

“Does mom do that?” I try to probe for the right behavior.

“No, She just talks to people without trying to be funny.”

I have a long way to go as Mr. Mom for my teenage daughters. On a second thought, I don't think I can ever be.

## ***20 -- A Letter from the Donor***

This time Sue has overstayed her turn in Minneapolis. She must because of Kyle's unfortunate setbacks. To minimize the time that Kyle is left without a parent, Sue and I decide not to meet halfway. She had asked the Rossbachs and Pete Carlson to look in on Kyle while I rush to be with him.

My mind is preoccupied by a possible work reassignment on the entire trip. Except for the Computerized Tomography (CT), it should be an easy day for Kyle.

His room is empty when I arrive at the hospital. The nursing staff directs me to the CT room in the basement. I get there just in time to see Pete Carlson come out. After a quick greeting, I rush into the room. Kyle is moaning and breathing hard on the CT table. The cover's rapid rise and fall reflects a jumpy, shallow breathing pattern. When I call his name though, his moaning immediately stops. I realize that Sue and I have underestimated Kyle's need for a parent. I am sorry, my son. We will not do this to you again. Tears well up in my eyes. I say to myself, “Son, you have gone through so much for something you did not ask for. You have always come back. Please do it one more time, my son.”

He trembles in great pain as his pancreatic inflammation gets worse. He would scream every time he is touched. On the pain scale of 0 to 10, he gives it a 10. I should have asked for more painkiller much sooner. Dr. Stella Davies wants to attack the source of the pain. She orders a tube to be inserted through his nose down to his stomach to pump out everything that enters it. This should give the pancreas time to rest. But the tube brought by the nurse is too large. She gives up after a few tries. We have to wait one more day. To see Kyle suffer like that is pure

misery.

Within one day of the tube insertion, the pain begins to subside. In the morning, I go back to the RMH to take a shower. Upon returning, I see a new stuffed animal dressed in a yellow rain coat staring at me from the foot of the bed. “What is this, Kyle?” “Who gave it to you?” “Is it from the nurse?” I fire off a bunch of questions at him but he does not answer me. Lying next to Gordon, the Beanie Baby, are a folded paper and an opened envelope. The thought of a gift coming from someone special suddenly jumps to my head. When I unfold the tan paper, it reads:

*Jan. 31, 1999*

*Dear Kyle:*

*I hope this letter finds you doing well. I didn't get your letter until January 12, 1999. It was great to hear from you and to know you were feeling better and doing good. I think about you everyday and you are in my prayers every night. It was nice of you to let me know a little something about yourself also. I have two daughters, ages two and seven. I also have a dog named Pongo. He is a three year old Dalmatian. I picked out a couple of Beanie Babies for you. I hope you like them. “Spike” is retired now. I am going to close for now, keep in touch—I'll do the same! I hope one day we can meet one another, my family and I would like that a lot! Take care!*

*God Bless,*

*Melissa*

A green routing slip is found on the nearby lamp table that contains the following:

*Date 2-2-99*

*Hello Transplant Center 506*

*This communication is from our donor. DID# 0085-8354-4*

*For your receipt id 947-672-2 Name Kyle Wu*

*Please forward at your convenience. Thank You!*

*Xxx Xxx, Donor Center 018*

The letter arrives at a time when Kyle is having great abdominal pains. “Dear Donor” is suddenly transformed into a flesh and blood mother with a family of her own. Her Beanie Babies are such a hit that Kyle gets up at 4 a.m. to write a letter back to her. Melissa, you are an angel, appearing at the right moment for the second time.

## ***21 - Writing Therapy***

Almost all doors in Unit 4A have some kind of information about the rooms' occupants. But Kyle's is bare. The last time I taped materials on the door was in Unit 4B when my son had his transplant. Some of the families have gone home and a few are leaving within days. I am still looking at two more months. I recall Bob's numb face that declared the end of hope for his only child. The scene of the sobbing relatives waiting outside Room 7 for that final moment still haunts me every time I walk by it. Then how can I forget that glee on Cindy's face when she told me she and Jonny were going home to Milwaukee? There was that unexpected encounter with the Colorado-bound Rossbachs on my way back to the RMH. They were coming to say good-bye to Kyle and me in the hospital. When their loaded van pulled away, I wanted to grab them to ask them to stay a while longer.

I feel so deserted and so empty. Although discouraged, I must move on for Kyle and with Kyle. I lock myself in the Family Resource Room to write a poem on the computer. Then I post it on the door:

***I am in a marathon though I did not choose.  
Whether I'd finish, no one knows.  
Hills and curves I must face,  
For months, weeks and many days.  
Friends and strangers all cheer me along.  
But I remember that wonderful song:  
Amazing grace how sweet the sound...  
I can go another round.***

Feeling that it is incomplete, I then add the rest below:

***Grunts are heard from near and far.  
Pains and anguish are just for par.  
Some seem to move like a breeze.  
How long can they maintain their speeds?  
Others just cannot finish.  
Hospice surely is not their wish.  
Gift of life can be a year or ten.  
But someday they will meet again.***

***News of finish I also hear.  
Rapid healing makes us all cheer.  
Whether I'll be in the group still,  
Trust and endurance will later reveal.  
Trial and testing make me strong,***

*For years to come and all life long.  
Making a difference is what I must do.  
To touch others through and through.*

Then I write another for the door:

*They say it's hard. We say we must.  
They ask how we do it. We answer one step at a time.  
They say they can't imagine. We say we'd find a way.  
They ask how they can help. We answer people like you already have.  
They say we are strong. We say we have no choice.  
They ask what our future might hold. We answer it is in God's hands.*

*We feel life is not fair. But to whom do we appeal?  
We wish for a healing. But we are still waiting.  
We feel it is taking too long. But the next door's is longer.  
We ask for a miracle. But will our child be the one?*

Except for Liat Rothfeld the pediatric BMT patients are fairly new in Unit 4A. I miss the support from those familiar "old timers". It is going to take a while longer to develop a new one. In the mean time, I am the voice of experience. To the new comers, we have become the high water mark for endurance.

## ***22 - Trickery and More Surgeries***

"You really have to watch your son," Sarah the nurse begins to lecture me as I return from a break.

She continues, "When you were gone, he told me and the nurse's aid that he wanted to use the bathroom. You know he had not got out of the bed on his own for quite a while. So we helped him to get in. He locked the door. We waited for quite a while before we asked if he was all right. He finally said yes and he was ready to come out. At that moment, we heard the sound of an empty paper cup placing on the counter. Suddenly, it dawned on us what he just did. He snuck a drink! He is not supposed to have anything but a sip because of his Pancreatitis. When we confronted him, he would not say anything. See if you can find out what and how much he drank."

"I think I know what he drank. He has been begging for a sip of the Gatorade in the last few days. I keep it in that room," I reply, eager to find out for myself.

Sure enough, when I check the bottle, it is about half gone. It was only a tad below full before.

“Boy, I’d hate to see him when he becomes a teenager. There is no telling what he might pull then,” Sarah begins to chuckle.

I snicker with her. I know many more sneaky things he has done over the years. He must be feeling much better to have done that. I am so delighted that I forget to apologize for him.

Room 9 has become a busy place during the day. The teacher and the physical therapist have to squeeze in between the many medical staff visits. The news of my son’s trickery has now spread to the doctors, interns and the other nurses. I am sure the staff is on high alert.

Kyle’s eyes are still dry even after the partial closing of his tear ducts. The artificial teardrop application every two hours is quite a nuisance. Dr. Christiansen now recommends tear ducts’ closing as well as sewing his eyelids to reduce the eye opening by one third. The procedure is reversible as I am told by another surgeon, Dr. Egbert.

“When will the surgeries ever end?” I ask myself.

Then I hear another voice say, “He has been through so many. So what is one more?”

The last two weeks has been the toughest for me so far. I have not seen Sue since New Year’s Eve--a six-week separation. We once again agree to meet at Perkin’s in Rockford for breakfast on Sunday when we swap places.

## ***23 - A Speeding Ticket***

Although the alarm is set for 3:30 in the morning, I awake up before then. I suppose the anticipation of seeing Sue is the reason. Much has happened during my two-week stay. She and I have agreed to leave at the same time--4 o’clock Central Time.

Except for a cold period from mid-December to mid-January, the temperature has been fairly mild in Minnesota. It is not much below freezing, and the drive should be rather ordinary. I am ahead of schedule as I travel through northern Wisconsin. The radio is on a Christian station broadcasting traditional hymns. They bring back many church memories in my youth. It is around 5:30. I find myself getting sleepy. I get off at the middle Eau Claire exit for a coffee break.

As I continue on southbound I-94, the coffee has not produced the desired effect. The grogginess has returned. It is still dark but the eastern sky is beginning to turn blue. Suddenly, flashing blue and white lights strobe the interior of the Neon from the rear. I am not sure if I have been dreaming. Then I realize that it is the police!

“Great, where did he come from?” I mutter to myself, “I have no idea how fast I have been going. Whatever it is, I hope he’ll let me go quickly.”

I pull over to the shoulder, still somewhat dazed. It takes forever for the officer to walk up to my

car.

He says to me, "I have been following you for a mile. My radar says that you have been traveling 14.5 miles an hour over the speed limit. For anything less than 15 MPH over...Let's see... the fine would be 147 dollars and 50 cents."

Shocked beyond belief, I can only manage to say, "That much? I don't have that kind of money on me."

"Since you are from out of state, we have to post a bond. You can use a credit card. Otherwise, we have to put you in jail," continues the officer coldly.

"Can you show some leniency? You see I have not seen my wife for 6 weeks. I have a son in the University of Minnesota Hospital. Today I am switching with my wife. She is coming from Michigan. We are going to meet in Rockford, Illinois at 10 o'clock," I begin to tell him my special story.

"You could contest this in the Black River Falls District Court, but you have to pay the bond first."

Wanting to finish my story, I continue to tell him the rest: "Officer, do you know that we had to raise money for my son's bone marrow transplant last year..."

"Well... Do you have the money or come with me?" the officer hesitates for a brief moment.

Seeing that he is not going to let me go free, I hand him my Visa card and my driver's license. Then I mutter: "I hope I can still make it to Rockford by ten."

As I drive on towards our rendezvous, I can almost see Sue's impish reaction in many ways and colors. My record of eluding a ticket is broken. She has been telling people how lucky I have been, given my nonchalant driving habits.

"Wait till Joyce finds out," I mumble to myself, "She is about to get her driver's license. And worse, she is going to tell her friends in high school. I hope I don't make the newspaper in Brighton."

I pull into Perkin's parking lot. My eyes keep sweeping for Sue's silver fern van. Finding none, I decide to wait inside. There is only one couple before me. I ask for a table right by the register so I can spot Sue when she arrives. In the mean time, I am debating whether to get a small cake for the Valentine's Day that we spent apart. I did not even send her a gift or a card this time.

Fifteen minutes later, Sue walks in wearing a sharp looking jogging suit, which I don't remember having seen before. Her hair is lighter, almost bordering on platinum. The purse she is carrying looks new too.

We exchange some information about happenings in the hospital and at home. Then I tell her about my speeding ticket.

“I thought there was something bothering you. I don’t go 5 over the speed limit myself,” Sue stops short of been critical.

“You know how much that ticket was?” I can’t wait to see her reaction, “One hundred forty-seven and fifty cents! Why the fifty cents, I’ll never know.”

“Prices have gone up. I’m not surprised,” Sue says without much emotion. She must have heard from others recently.

“I’m going to appeal this because of our special situation. There is nothing to lose,” I reveal my intention and logic. “If I had invested in a radar detector, I might have avoided the whole thing. It should not cost as much as the ticket.”

“Go ahead but drive slower,” Sue lightly admonishes.

“I could not get hold of Julie or Pete. So I asked Dany to check up on Kyle today. Are you going to see him when you get there?” I am trying to feel her out.

“No, I will be too tired. Kyle knows I will be with him in the morning like previous times. He is doing OK. Right?”

“Yes. But I wouldn’t feel right if I did not go see him right away,” I counter.

“You are not as exhausted as I am,” Sue retorts.

The long distance driving has become an old hat. Several times on this trip, I have to slap my face to stay awake. As I approach Kalamazoo, even the self-inflicted pains have lost their sting. I pull into a rest stop to take a nap in broad daylight. But I only manage to do it for about 15 minutes though. The noise made by other travelers combined with the need to take Shila to deliver the paper have kept me from a longer one.

I took quite a few pictures of Kyle during my last stay. It is about time I should update Amy Kemnic of the Brighton Argus and Stephanie Koehn of the Ann Arbor News. I know our church would want to hear the latest too. I quickly type up an update and leave a copy with the church receptionist. Then I drop the same information on Kyle in Amy’s mailbox along with a picture. Amy calls me the next day to ask a few more questions before she completes her Argus article. She decides not to use the picture. I must admit that the white steroid cream smeared on that large bloated face makes Kyle look like a creature from the outer space. But, at least, what Kyle has endured in the last month and half is on its way to the public.

## **24 - Never Give Up**

I am still trying to go through the mail stack. A hand-addressed letter from Mrs. L. Newland on Aberdeen caught my attention. Aberdeen is about a mile away. I remember Kyle having received a large envelope with a poster-size letter in the hospital from someone with that last name. It was from a boy in Brighton who fought for many years against various debilitating diseases including a bout with a flesh eating bacteria where the infected muscles had to be cut away.

This incredibly tough and eternally optimistic mother tells us again in much more detail the story of Tyler, who has already lived 5 years longer than he was supposed to. His struggles make ours pale by comparison. She also includes a poem written by Tyler titled:

### **Hope**

*by Tyler Newland*

*When I'm lying in bed at night  
and have trouble going to sleep,  
I think of all the things I'm sacred of  
and give them to God to keep.*

*He will listen if you're really sad  
or have something you want to share.  
He will give you all his time and love  
and keep you in His care.*

*So when the times seem really bad,  
you don't have to be afraid.  
Just keep thinking it will turn out right  
and remember the promise God made:*

*To keep us safe and love us  
to see us through bad days.  
The more I think I'm all alone,  
the closer to me God stays.*

*So try and see the sunshine.  
Let the hours be filled with hope;  
God will sit beside us,  
and He will help us cope.*

I feel drawn to this well of inspiration. And, maybe, just maybe, the Newlands might have a need that I can fulfill. I drive to the address on the envelope. The garage door is closed. However, the full size brown and tan van in the driveway gives me the hope that someone might be home. I ring the doorbell. Then I hear a rustle. A rush of anticipation perks up my entire body.

“Hi, I am Kyle Wu’s father. Are you Mrs. Newland? I got your address from the letter you wrote. I have been wanting to meet you and Tyler,” I introduce myself.

“Oh yes, I am Ladny. Please come in. Tyler is in the other room. Don’t mind the stuff scattered around the house.”

“Your letter is such an encouragement for us,” I continue our first face-to-face encounter.

We enter the kitchen. The TV is on a kids program. “This is Tyler,” Ladny introduces me to a boy looking no older than 12 or 13. He looks up at me curiously, head tilted. His bright hazel eyes beam like a beacon. I take his deep mumble as “Nice to meet you.”

“Your mom told us so much about you and your brave battles.” He blinks his eyes and makes another sound from the wheelchair.

“Tyler is seventeen and he goes to Brighton High School. He can not hear, ” Ladny takes over the conversation, “As you can see, he still watches TV programs for younger kids because that is where he is maturity-wise.”

“But the poem he wrote tells me that he has been places only a few have,” I quickly point out.

“How is your son doing? He has gone through so much according to the newspaper. Tyler went through a few similar battles.”

“He has gotten over most of his infections. He is being treated for the Epstein Bar Virus Lymphoma which is a result of having been exposed to the Mono Virus while his T cells were depleted.”

“Are they your daughters?” I ask as I stare at the portraits on the wall.

“Yes, these two have graduated from college already and this one is still going to Michigan State. They all have supported themselves through college since I am a single mom.” I take a gulp, letting my admiration reach its peak.

Then I pop the question “Is there anything you need or I can do for you?”

“The only thing I can remotely think of is a new van to take Tyler around. This one has over a hundred thousand miles but it still runs fine. I wonder for how much longer though.”

“Have you mentioned this to any organizations in the community?” I try to suggest an idea.

“Our story is old and established...”

“Well, I feel so much better now that I have met you and Tyler. I have truly been blessed by this visit.”

“Don’t give up and trust in the Lord,” exhorts Ladny.

“I’d like to stay in touch,” I respond as I walk out of the door.

“Please do.”

## ***25 - Hospital’s Revolving Door***

Sue has been asking why I can’t spend more time in Minneapolis with Kyle. Up to this point, my shift has been no more than a week and a half. She is trying to tell me that she needs a quicker relief. After all, she spent over a month with our son in one stretch in January and early February.

Although they have not told me, Joyce and Shila show signs of missing that special mother-daughter bond. The employees and the supervisors in my department have been doing an admirable job to accomplish the goals we set last year. My laptop computer linked to DaimlerChrysler and the outside world makes it convenient to continue a part of my work from Minneapolis. I finally agree to do two weeks from now on.

For a change, I check out several cassette books for the upcoming trip to Minneapolis. I am excited about the radar/laser detector I bought, expecting that it should pay for itself either on this trip or a later one. My youth rebelliousness has resurfaced since the speeding ticket last month.

The Great Gatsby is an easy listening material. I find the F. Scott Fitzgerald’s story full of fast moving details. His writing style is truly “Literature”. The other book is Hunt for the Red October. I have decided to leave it for the more boring return trip.

My boy is still in Room 9 of Unit 4A. He has no discomfort, but the Graft vs. Host Disease has flared up on his skin. The steroid dosage is bumped up to counter it. Mrs. Arndt still comes to his room to tutor. Physical and occupational therapists show up on alternate days. Solid foods are starting to stay down again.

For reasons that I can’t detect, Kyle wants me to sleep in the room. This continues for three days. I have brought my laptop computer in the room to communicate with people at DaimlerChrysler. It has become more difficult to fight the tedium since I recognize all and know most of the personnel that come in the hospital room. Writing this book on the laptop continues to give me a purpose and has become an emotional outlet.

The doctors are ready to discharge him for the first time since January. It has been quite a while since he slept in our apartment. I begin to take back the letters, cards and gifts. Although this is a

good news, spending two more months just to end up where he was in early January is a bit discouraging.

Still, watching Kyle put on his street clothes and tie his shoes gives me a sense of thanksgiving and accomplishment. As I push him in the wheelchair passing the rooms, memories begin to flash across my mind. One by one, I attach a mental label to each of the rooms: “Good”, “Bad”, “Sad”, “Easy”, “Struggling”, “Any minute now”...I wonder what emotions my boy might be experiencing as the wheelchair bumps open the double doors--perhaps leaving Unit A for the last time. Then it is the elevator, lobby piano, Espresso Bar and front desk...The air blows briskly on face. I must be moving at a faster pace than I care to admit. Perhaps it is trying to tell me to wake up to a new beginning even though I have been reluctant to count on it.

The shuttle drops us off at the RMH. Kyle shocks me by ignoring the wheelchair and walking doggedly to the elevator with me trailing behind. He then proceeds to our unit on the third floor. I suppose he is determined to find out if he is still strong enough to do it.

When he gets inside, he heads straight to the queen-size bed. His eyes disappear in a big grin as he sits down on it. Then he lets out a sigh of relief. I realize at that moment what the bed has meant to him: the most personal, comfortable place at the end of a long journey.

I wake up in the middle of the night only to find Kyle missing in bed. We sleep together so that I can respond quickly. The light is on in the loft where he used to sleep.

“Kyle, are you up there?”

“Yes, comfy. It is my bed,” he answers in a cuddly voice.

“You know you must come down to use the bath room. You are too weak to do that fast. The sheets and the spread are clean. Now your mom or I will have to wash them again. Your mom won’t be happy when she hears about it.”

“Mm mm” is his response. The sound suggests that he is really settled in.

Seeing that I can’t convince him to come down, I go back to sleep.

“Dad, my stomach hurts,” Kyle complains as he hurries to the bath room, “I want to throw up.”

When he comes out, I put my hand on his forehead.

“Let’s see... You feel warm. You have a fever! I have to take you back in the hospital.”

When the nurse checks his temperature, it is over 100.5. That means he must be re-admitted. Here we go again. Cultures are taken immediately to find the source.

Having not had a repeat and with the cultures turning out negative, Kyle is discharged one more

time.

The stomach pain returns two days later. This time my boy is crying. I give him a pain pill with Codeine, which he throws back up. When I take the temperature, it is 99.6 and rising. I ask the hospital to page the doctor on call since it is already after dinner. Dr. Woodward agrees that Kyle should go in. He says he will ask the hospital to call me when a room is ready.

Having not heard the phone ring after two hours, I take him to the hospital at 9. It will be much safer for him to wait there. When we arrive at Unit 4B, we are re-directed to go to Unit 5A – where the room is going to be. A nurse takes us to a conference room where she begins to take Kyle's temperature. The thermometer now registers a 102. There is no doubt that I did the right thing. A room is finally ready at midnight. I get back to the RMH to sleep around 1:30 AM.

The attending physician Dr. Wagner insists that this time he is going to keep Kyle in longer. I would have asked for the same. These “in and out” trips are stressing me out. However, the source of the stomach pains remains unknown. But I remind myself that I have let go of the anxieties as I did few months ago when I was taught the lesson in the Tao of Pooh.

It is time for me to return to Michigan. The radar detector has not earned its keep on the way up, but I am still hoping. It has been a quiet trip so far. Anticipation builds as I travel near Black River Falls, Wisconsin--the site of my speeding ticket. I get into the state of high alert with ears perked and eyes wide open. But there are no cops. The radar detector has stayed silent throughout the stretch--what a bummer.

The signs tell me that I am near Chicago. Like my previous return trips, I switch the radio station to one that plays Mexican Music. The sound is unique. It reminds me of the fifties. Not soon after Chicago, I pull out the **Hunt for the Red October** cassette. The story starts slowly in the Russian Navy. The intrigue builds as I cross into Indiana. And then, as I get closer to Michigan, it explodes into a high drama of a cat-and-mouse game. I feel like riding an adrenaline roller coaster, complete with white knuckles. My heart jumps out of my throat many times. The tape ends just as I approach Kalamazoo. I exit at the Airport Road for a quick stop.

## ***26 - Coming Home***

After having been kept in the hospital for a longer observation, Kyle is again discharged. At the same time, the doctors are starting to treat his Epstein Bar Virus Lymphoma with Rituximab. The program calls for a series of 4 weekly chemo doses.

Both Sue and I are quickly reaching the limit of our endurance. Sue begins to talk seriously about bringing Kyle back home to continue his care at U. of Michigan. Nurse Micky encourages Sue to ask Dr. Peters if he would consent to releasing Kyle before Easter.

When Sue brings up her wish and the subsequent follow-up care at Michigan, Dr. Peters agrees to begin the transfer. It just so happens that Dr. Peters worked at Michigan for three years prior to

joining Minnesota. He knows the staff well. The condition for release is that Kyle has to show negative VRE cultures for three days in a row. The big milestone that escaped us in January now appears to be within grasp.

Signs of spring are popping up everywhere. Bed half-empty, I wake up daily to the incessant chirping of the returning birds. In broad daylight Forsythia blooms stand out like trees with brightly lit yellow lights against the immense, still lifeless landscape. Sunrays pierce through the warm air as if a thousand flares had been shot up. Yes, the smell of the coming Easter is unusually irresistible this year. It has an added scent: the possible return of my own son to begin a new life. We have all changed--having been through life's Boot Camp.

Can it be true? It is March 31. I have to pinch myself when Sue tells me that her minivan is packed and ready. A room with a refrigerator at the Rockford Courtyard by Marriott has been reserved for an overnight stay. All Kyle needs is the OK from Dr. Peters at the clinic in the morning.

I was, and we were disappointed once before. But this time I can feel the momentum. It is impossible now to beat back the waves.

Sue calls me from her car phone near Kalamazoo around 3:00 p.m. on the 1st. I move the pin on my mind's map one step closer. They are caught in the traffic though. The ETA suddenly changes from 4 or 5 to TBD. The waiting anxiety now gets even worse since I spent the night before and the entire morning decorating and putting up a "Welcome Home" banner, yellow ribbons, flags, in-ground signs and balloons. I don't want them to miss the extravaganza in the dark.

The back door from the garage swings open at 7:10 p.m. There is still light outside. Behind Sue is a slow moving Kyle, struggling to step into the house that he left more than 6 months ago. We take turns to embrace him while the dogs bark in excitement. I am not sure if they do that because of the commotion or forgetting who he is. Joyce and Shila urge him to go up to his room.

Much is waiting there for him. Being so weak, he has to crawl up. I close my eyes to collect myself before I join him.

The gift-covered bed comes into view as Kyle enters the room. There are so many that he does not appear to know which to touch first. Stashed in the corner are several boxes of old well wishing cards. Sensing what is needed, Shila hands a gift to him and starts to separate the rest into groups. That seems to have broken the ice. One by one, he flips through them all.

Can an 11-year old truly understand the meaning of it? Will he remember the efforts of the fundraisers? Are they merely fleeting incidents, of which I have to remind him? Will he ever ask about my sleepless nights? One day I'll tell him my anguish of asking God to take the pain away. I'll tell him again and again how brave he was. I'll even tell him the doubt I had of God's very existence. Did he feel the touch of hundreds or was it just gifts and cards? Did he only see the money in the envelopes as things he could buy or something much more precious? Someday,

when we talk, I will know.

Behind these kind gestures are hundreds and hundreds of hours of buying, wrapping, writing and sending. I hear thousands of prayers. I feel the constant out-pouring of empathy and support even to this day. What makes people do that? Do I just call it the best manifestation of humanity? Are people capable of doing that without a divine cause? Having been touched, how will I respond to other similar situations around me?

Ann Arbor is only twenty some minutes away. Kyle is now under the care of Dr. Hutchinson and his staff. As Sue pulls her mini-van in a spot in the Taubman parking structure, we both spot Alana Staynar hurrying passed us, apparently heading for the Mott's Children Hospital, the same place we are going. What a coincidence! The Staynars spent about 4 months in Minneapolis in the same Ronald McDonald House. Their two-year old Zak went through a cord blood transplant for his Hurler Syndrome.

The visits to U. of Michigan has gone from daily to twice and now just once a week. The tutor Chris comes twice a week. Therapist Dana's mother, Mrs. Pederson, is an office assistant at DaimlerChrysler. She knew about Kyle's story when it first came out last year. It is a small world in many unexpected ways.

He is still on Rituximab. Prednisone is again being tapered off after a bout with the Graft vs. the Host Disease in early May. As for me, the book of life is flipped to a new chapter. How will it continue depends, to a large extent, on my character, my faith and my relationship with those around me. As for our son, he is in God's hands. Ultimately, aren't we all?

To those that had the courage and endurance to go through a transplant at Minnesota and that special boy of incredible quality and strength: I will always remember you because we fought that enemy called **Life Unfair**. I shed tears when you dropped. I cried out for help when you fell wounded. I shouted encouragement when you got tired. I rejoiced when you came around. Here are my salutations: Looking good, Zak Rossbach of Monument, Colorado. Liat Rothfeld of Haslett, MI, welcome back to life. I am looking forward to seeing you. Good-bye, Kylie Rossett of Minnesota. But I will always remember your beautiful face. Jim Schmitt of Buffalo, remember that special oil swatch. I'm still waiting for that miracle. You put up a long fight, Candace Koehn from Kansas. Little Zak Staynar of Livonia, MI, may you continue to be comfortable at home. Hope to hear about your driver's education in Kansas, Derek Bakeberg. Tiny Emma Winograd of New York, you had incredibly optimistic parents. They gave you all they had. Tommy Reis, you did well, and I hope you do even better in Florida. Jonny Kuderer, break a record in recovery in Wisconsin. You broke the hearts of many, precious Annalisa Bevilacqua of Balto, Maryland. Cute Tyler Pavlik, you will make a good poster child for BMT in Madison. Erin Evans of Iowa, you gave Kyle and me the confidence to go through the transplant. Katie Deauville, I hope to see you in San Jose, California soon. My brother and parents live not too far from you...And, Jo Claypool, like your father says, you are just having a long sleep...

**Looking Back after Kyle's Death on November 22, 1999**

It is strange: although Kyle's recovery was never guaranteed, the possibility of death never came to the surface. His fevers averaged about one a month during the summer, which to me appeared to be only bumps on the road back to health. Optimism prevailed in that entire period. There was no emotional fuel to add to what I had written. However, Kyle's passing changed all that. Upon the urging of many and having been freshly branded by Kyle's last struggles, I have finally decided to write more. The memories and feelings from May to October of 1999 have to be thawed out from recollection while those in October and November are as fresh as gushing water from the spring of life. Where it will end I do not know. Allow me to continue my account in the present tense.

November, 1999

## ***27 - Breaking Out***

"Michelle, I think Kyle is strong enough to make a brief appearance at the Junior Church next Sunday. After all, the kids have been praying for him all these months, not to mention all the cards and gifts," so I say to Mrs. Beaker when I run into her in Church.

"You know, I have been wanting to contact you to do the same. You see, the kids have just signed a gigantic Welcome Home poster, and we want to present it to him," responds Michelle excitedly. She is always so upbeat.

"What about next Sunday? We will make that a surprise visit. You and Kyle wait in the side room...Let me see...at 10:30. When you hear the announcement, you bring him out to the front," continues Michelle.

"It sounds great. I can't wait to see the reaction from the kids. Kyle has wanted to see some of his friends ever since he came back and has wondered when he can attend church again."

Sunday comes too quickly. I can see the anticipation on his puffed-up dough boy face. The invisible cloth of excitement is draped over his entire body. This is going to be the first time Kyle sees the kids since last September.

Slowly, he stretches his mask on, then the eye-glasses and, finally, the hat to cover his nearly bald head. The Rituximab has kept the hair from growing back.

The short drive feels like many miles more. We are taking a risk to let Kyle face such a large crowd. The urge of showing up at church overtakes our caution for once.

Through a sliver of an opening, I see the backs of the kids and a part of the program. Mrs. Pond and Mrs. Jeanette Prisk are on the stage talking about Jesus. The wait is longer than I would like, and I begin to worry if my son can stand up any longer. The chapel was still being built when Kyle left 7 months ago. The sight, sound and smell must all be new to him.

“We have a special visitor here today. He can not stay long,” announces Mrs. Prisk. “Here is Kyle Wu!”

Blood gushes to my head as I slowly leads my son out from hiding. I can almost hear the gasps over the thunderous applause. All eyes are on the covered-up boy with a big belly as we slowly walk up the side aisle. After I thank the children and explain the slow process of recovery, the large poster is presented to Kyle...

“I did not see any of my friends in the crowd,” Kyle says to me in a disappointing voice when we get back in the car.

“Sorry, I was not looking for them. Some of them must have been there. It is hard to pick them out from so many,” I try to be comforting.

I run into Mrs. Pat Hatfield unexpectedly at K-Mart. She is the head trustee for the ALD Trust Fund that we set up for my son last year.

“Hi, Pat! I have a surprise for you,” I can barely hide my excitement, “Kyle is riding in an electric cart somewhere in the store! I’ll get him over here to see you.”

Equally excited, Pat says, “I’m so happy that he is back. What a relief it must have been for you, Sue and the girls!”

I quickly step into the main aisle to look for my boy. Spotting him, I shout out, “Kyle, come over here! Mrs. Hatfield would like to see you. She is one of the moms who are taking care of your medical trust fund.”

Of course, that does not seem to mean much to the 11-year old.

When he pulls up in the electric cart, I begin to explain it to Pat, “See, how different he looks now. The steroids and the chemo have done that to him. We let him come to a store when is not crowded...”

“Hi, Kyle, so nice to see you. This is Curtis and that is my older son Brad. Brad and Curtis, this is Kyle who went through a bone marrow transplant.”

At the end of our brief encounter, feeling a bit sorry for myself, I then murmur something like “You are so fortunate...and count your blessings...”

“Since Kyle missed the fifth grade dinner last night as a surprise guest, I took him to Spencer today for a brief visit. It just so happened that the kids were having a field day outside. But when we got there, the entire fifth grade was inside eating,” Sue begins to tell me about the make-up surprise one day in May, “The kids surrounded him but were asked to keep a distance. Some climbed on tables just to be able to see him. A few were jumping for joy. Alex Peterson, Brian Switala, Adam Gandolfo and Andy Williams came round to his backside. Because of the mask, I

had to repeat what Kyle said to the crowd. It was quite a scene.”

Oh, how I wish to have been there to capture this Norman Rockwell moment on video. Now we only left with the memory.

## ***28 - Nine Month Check-up and Adam G.***

Because of Kyle’s extended stay in Minneapolis, the standard 6-month check-up is replaced by the 9-month. July 5<sup>th</sup> is the date for his return visit. Ever since he came back, I have wondered about his progress toward a full recovery. This trip should give an indication. Since Sue knows the most about Kyle’s ups and downs and the medication history, we decide that she will take him.

Nonetheless, I am leery of how they might handle the long drive back to Minneapolis since Kyle is medically and physically fragile. One thing I have always admired Sue for is her fearlessness and confidence. The years she worked in the doctor’s office taught her that.

According to Sue, Dr. Peters’ over-all assessment is that Michigan has been doing all the right things. I take it to be good news. However, what is disappointing is that his return to school is further delayed. It cannot happen until he has been steroid-free for 3 months. Still, I am hopeful that my son will eventually go back to Spencer. It looks like we will have to ask for an in-bound teacher for a part of the school year...

“You know what our insurance coverage is for physical therapy? We have already used up the in-home sessions. From now on, I have to take Kyle to Novi Providence. We are going to try three times a week. Once started, it is good for 60 days,” Sue tries to alert me to the reality of the life outside the hospital.

Then Sue has another idea, “What we can do is to get him an exercise bike. I’ll check with Pat to see if the trustees will agree to pay for it.”

“Good, in the mean time, I can take Kyle to MC Sports or Dunham’s to find a model that will fit him,” so I volunteer.

Trips to places not crowded continue. I learn one day that Sue took him to a matinee to see the new Star Wars movie...

“I am going to the store. Kyle, would you like to come along?”

“Sure, Dad. Can we bring the pop bottles and cans? I like to put them in the deposit machines,” answers my son.

“Don’t forget your hat, the mask and the gloves,” I quickly remind him.

Kyle enjoys short trips to supermarkets to do simple tasks such as this. He finds even more satisfaction in exchanging the receipts for money from the cashier. Bagging the newspaper for Shila and Mom is another chore he does not mind doing. Communication with his donor continues although the letter delivery is slow. They have to be cleared and resent by Minnesota so as to keep the parties anonymous.

School is about to begin. Kyle seems to be getting stronger and a bit restless. The visits to U. of M. have been cut to once every week and a half. One day, he is so delighted to receive a letter from Adam Gandolfo, one of his best friends in the 5<sup>th</sup> grade. Before the transplant, Adam's mother gave Kyle two dwarf hamsters, which he named Pepper and Tanny to enrich his life. Adam's letter reads:

*Dear Kyle:*

*Hi! I hope you had a good summer...Have you heard about Pokemon cards yet? Well if you haven't, there is a couple in this envelope. Hopefully we can get together soon, and I could show you how to play...I am playing roller hockey now, and out team is really good...Cards in the envelope are Pikachu, Charmeleon and Charmander...and wish you luck in 5<sup>th</sup> grade.*

*Your Friend,  
Adam*

This is how Kyle replies:

*Dear Adam:*

*How is 6<sup>th</sup> grade at Scranton Middle School? I am having therapy in Novi, and I am on a lot of medicine. Some are really nasty. I am starting to have the teacher to come to the house really soon. Her name is Chris West. The hamsters are doing really great. Maybe some day soon you could see them...When I go to college in 9 years, I'm thinking of MSU or Wayne State like my dad...Have you heard that Aaron Kopcyk and his brothers Tommy and Kyle are playing roller hockey also?...*

*Your Friend,  
Kyle Wu*

“Kyle, do you want Dad to take you to visit some of your friends? Who do you want to see besides Adam?”

“Andy Williams. His house has a red front door. Brian Switala and...Aaron Kopcyk...” Kyle slowly names the kids. It has been a long time since he last saw them, and I have wondered why has not begged to see them. Perhaps he is self-conscious about his appearance or his condition. I have often probed but received no answers.

We pull up the curvy, uphill driveway cut through the pines. The garage is open but no one is outside. Within seconds, two men come out of the back door.

“Is this the Gandolfo house?”

“Yes, you must be Kyle’s dad. I am Frank and this is my brother-in-law...,” says the man with redish blond hair.

“Kyle is with me. He has been wanting to see Adam.”

“Oh, wonderful. Hi, Kyle!... Adam and Angele, Kyle is here!” yells Frank towards the house.

A string of people starts to come out, eyes and mouths wide open, all staring at the car window.

I open the Neon’s rear door to let them see inside. But Kyle remains quiet so I have to do most of the talking for him. After a while, he begins to open up and says a few words through the mask.

The visit is brief and yet momentous. This is the beginning of his social recovery.

A few days later, because of a fever and a cough, we have to again admit Kyle into Mott’s Children. Pneumonia is the cause this time. He is discharged a week later...

The new-found interest in Pokemon cards has taken over the Beanie Babies. Kyle is again looking forward to going over to Adam’s to learn more about them. I am only too happy to oblige. Once there, we are invited to sit on the porch with the entire family as the sun starts to set.

“Kyle, you look good. I can tell that you are getting stronger. Pretty soon you can go back to school,” so greets Angele Gandolfo, “Guys, what do you like to drink? Is lemonade okay?”

“That sounds good,” I reply, noticing that Adam and my son are sitting next to each other going over a stack of cards. The soft voices of the two young friends provide the back drop to the conversation the adults are having. The frequent giggles only tell me how much they are enjoying each other’s company. Here is another scene worthy of Norman Rockwell’s skills. If it were not for his bed time, Kyle would want to stay there much longer.

We pull in the garage just before dark. My wife is not happy with the time of our return -- an hour passed his bedtime. I promise then that I will pay much closer attention from now on. Would she have felt that way if she had seen the joy between the two boys? Sue, I wish you had been there.

## ***29 - Getting to the Bottom of It***

Kyle has slept for two days. He refuses to take his medicine or to eat. His temperature is

climbing. Now we have to take him in. This time, I insist on tagging along. I have been wanting to learn the emergency check-in routine. Because it is so dragged out, Sue has convinced me not to waste my time. Just like what she has been telling me, my son is finally taken to his private room after 6 hours...

Dr. Yanik has a dry sense of humor. Sue has always looked forward to having him on duty. This time both feel that Kyle should not be discharged until the mystery is solved. A core sample of his marrow is tapped from his pelvis for analysis along with a battery of new tests.

Since the doctor visits the patients in the afternoon, I have to rely on Sue to relay the findings piece by piece to me. Kyle's condition does not look good. I sense the gravity of the coming prognosis.

Having enough data now, Dr. Yanik asks for a consultation with Sue and me. We set it up for noon, Tuesday. I run into Cindy Bower in the hallway just before the appointment. She is my son's out-patient nurse practitioner, and we have not met.

Sounding regretful and feeling like a messenger of bad news, she says to me, "Mr. Wu, Kyle's new marrow just did not have a chance to grow since he developed the Epstein-Bar Virus Lymphoma soon after the transplant. You know the chemo that treats it suppresses the marrow growth..." Her face and her shaking voice paint a picture of little hope.

After a delay, Dr. Yanik eventually meets us in the conference room at the end of the hallway. From the top of his head he starts to list and spell out his findings.

"There are 7 serious conditions Kyle is facing..." Dr. Yanik starts to describe them one by one in detail. It is as if I were hearing the judgment at the end of a lengthy trial...

Toward the end he says, "You might ask 'Has anyone who was in a similar situation recovered from it?' The answer is yes. I know of one girl." When he says that "yes", he grabs his own head and tips it up and down. Although that gesture lightens up the atmosphere, I am again reminded of the long odds. Hope has kept Kyle and us going for the last two years, and, at least, there is a glimmer still.

"What kind of life is that girl leading?" follows up Sue with the last question.

"Other than a minor limp, she is living a normal life."

### ***30 - "When Will I Be Normal Again?"***

Dr. Cooke now is on duty. He joined the staff from Harvard several months ago. Both Kyle and Sue get a big kick out of his East Coast way of saying things. Like the doctors before him, he continues to find ways to lower the steroids and change the medication around to promote the growth of the blood cells. Kyle's condition continues to challenge the staff with no end in sight.

One night he starts to scream from having great pains in his arms and legs. The standard pain killers simply do not help. I rush to the hospital at 6:00 in the morning to be with him. The mid-night nursing staff could not do anything more without directions from a specialist. I ask that he

be paged, but am told that he soon will be in.

I feel like I am in hell -- to hear the screams and not be able to do something about it. All I can say to my son is: "Kyle, the doctor is coming. They can't give you any new painkillers until he gets here. Be brave and strong for a while longer. You went through so much before. Can you do it once more?"

My suffering boy cries out, "I'm chicken...Call me chicken...I'm not brave...Oh, oh...oh..."

I can't take it anymore. With tears in my eyes, I step outside just so the crying does not pierce my head and my heart...

As the pains in his arms disappear with increased steroids, Kyle's blood pressure goes out of whack. My boy is getting discouraged. He has been looking forward to going Trick-or-Treating with Shila this year, but now must accept something different. Craft activities provided by the social workers seem to pick up his spirit. For several days he stays up quite a long time just to finish painting Halloween carvings and pumpkins...

Just before the weekend, Sue tells me with excitement that our church has arranged a surprise visit by Michigan's quarterback Drew Henson. Drew is a two-sport hometown hero from Brighton. He also plays for the Yankees. Hearing that, I rush out to buy a football while Sue finds a brand new baseball from my collection.

When I step in the room Monday after work, all I want to talk about is the visit. My wife is eager to recap the event for me as well.

"Drew came into the room with a brunette. He introduced her as a friend. He was surprised that I still remember his high school student number. He is really a nice kid. I also remember that one time he did not have enough money for lunch. I told him that he could pay me back. He did the next day. He is trustworthy. You know, after he signed the balls and the shirt, Kyle asked him to visit another patient in Rm. 17 because he had learned that the boy was in bad shape. Kyle has a kind heart and has been praying for that boy. Oh, by the way, Michelle Beaker was here when Drew showed up..."

My son must have reflected on his young life many times in the passed year. Out of nowhere Kyle reveals his deepest desire to my wife, "Mom, I would like to meet my birth mother someday."

Feeling more relieved than surprised, Sue replies, "Sure son. I have been wondering for some

time now. You know, Joyce and Shila never have expressed that wish to us even after I asked. After you are healthy again, and when you are old enough, Mom and Dad will take you back to

Korea, trying to find her. You know, more than a year ago, when we were searching for a marrow donor for you, we begged Holt International to look again for any trace. They again told us there is none.”

When life looks dark and gloomy, I suppose a child clings to the people, pets or objects that are dearest. I don't think it is possible for my son to remember his birth mother, but her mere existence is a bond that can never be severed by time or circumstance. Kyle, you bring out the emotions and pains like no one else...

“Mom, when will I be able to play soccer? When will I be normal again?” Kyle has asked my wife a number of times off and on. His mother always answers, “I don't know, but if you just do what the doctor says: eat, take the pills and try to move around, you should have a better chance. Why don't you ask the doctor?” Hearing that yearning and then looking at my young boy, I have to fight back tears to ask God for a miracle. How can anyone not be touched by that innocence? Isn't that genuine enough for even God to change His mind?

### ***31 - Inner Struggles, More Visitors***

Pastor Tweedie and I finally hook up for a lunch at Denny's in Novi. I, along with so many, have been petitioning God for my son for two years now.

“Brian, I have been struggling with the attitude that I should have when I pray. I would do anything to ask God for a miracle, but I also know that He may not grant me one.”

He responds, “I think I can help you. I read a book some time ago on that subject. What the author presented has helped me a lot. She had struggled with that question until the revelation. She was alone in a woods one day. In front of her were two separate huge tree trunks. But as she began to look up, the branches started to join together. It came to her that one's wish and God's plan will come together in a different plane or later in time... Pour your hearts out first, but always end up asking that God be glorified by the outcome...”

When I come back from the hospital, Sue asks me how the lunch went. I repeat what Brian said about the attitude one should keep in prayers. Then Sue mentions that Kyle has dreamed of seeing Papaw several times recently. I wonder if this is the message that God is trying to send us. Nonetheless, we can't give up.

Dr. Cooke comes into the room with a medical team -- a fellow and two interns.

“I wish I knew more about what is really going on in Kyle's body. The X-rays, CAT scans and tests can only tell us a few things but I would need more,” laments Dr. Cooke.

“How about a lung and a liver biopsy?” I suggest innocently.

“In his condition, it would be a risky procedure, but there is a time we just have to do it.”

My son never has had it easy. One more is just something he has to endure.

Kyle’s lungs begin to wheeze. Breathing treatments are ordered. Although it is an exhausting struggle, he is forced to get out of the bed to sit up as much as he can. It is good for the lungs.

Torrey, our Westie, has been my boy’s favorite dog. When he carries a long conversation, he invariably mentions it. On the bulletin board in the room are two snap shots of that playful white terrier. Outside on Room 29’s door hangs a full-length portrait painted by Child Life’s Adrienne Rudolph.

Kyle’s spirit and physical condition have deteriorated further. Sue found out recently that we could bring a dog to the hospital, provided we follow the rules. The time for the visit is now. One hour is the limit though. Joyce agrees to bring the dog in and take him back on Sunday.

The anticipation builds as the one o’clock visit approaches. The click of the door and Joyce’s voice telling Torrey to wait break that silence. The moment is simply magical. It brings back the excitement I felt when Kyle stepped into his home for the first time in six months just before last Easter. The whole world just seems to be innocent and whole again. I wish the ticking of time could simply stop. It is not too much to ask, is it, Lord?

The nebulizer treatment is increased to every two hours. Kyle’s breathing has become labored. A chest X-ray is ordered for Tuesday. It looks like a lung and liver biopsy will be a certainty. The option of implanting a feeding tube is being seriously considered as well.

Kyle is again looking forward to Michelle Beaker’s visit on Tuesday. The Middle School Ministry Director from our church has been coming once a week, except this time she has brought with her Kermit Morgan, with whom I had worked at American Motors years ago. The drinking of the X-ray dye is usually a chore for my boy, but their presence somehow makes Kyle a willing participant.

We received a consent form from Minnesota’s Bone Marrow Transplant Program a few weeks ago asking Kyle if he would reveal his identity to the donor. Just like Melissa, we have wanted to from the very beginning. However, for all that has been going on, Sue has not felt the urgency to ask him to sign it. I again remind Sue to do so, and she finally hands it to Kyle. Michelle Beaker counter-signs it as the witness.

Sue calls me at work in the afternoon to ask me to stay over night to ease Kyle’s anxiety. She will cover the following night. As the mother, she always senses the need. I still remember vividly the grueling nights that I stayed with my son in Minneapolis. What’s a few more?

“I can never get you two together--you and Sue, so that I can talk to you both at the same time,” complains Dr. Ferrara lightly soon after I arrive in late afternoon.

“That is how we have managed our family affairs in the last year or so. We are a relay team, but you can do it with just me. We agree on almost everything,” so I explain.

Looking a bit concerned, Dr. Ferrara continues, “I just want to say to you both that there is a chance that, after we do the biopsies, Kyle should remain under sedation until we know what he has in his lungs and the liver.”

It sounds terminal. And yet, I find myself taking the news calmly. If Sue were here, I would expect the same.

I reach Kyle’s room at about 3:30 p.m. on Thursday. He is in pain. I can hear him from outside. Sue is next to him to provide some comfort. I see my boy reach up his right hand to touch his mother’s face for support. The image of those long, tender fingers cupping his mother’s left cheek eats me up. My vision turns blurry. There I stand helplessly, just long enough to let myself be branded by that tender picture.

Sue comes out to inform me that the biopsies will be done tonight, but the time is up in the air since the surgeries are still being juggled around to meet patients’ needs. The feeding tube is on hold though.

For some reason, I hug Sue a bit longer for a good-bye. Kyle is wearing an oxygen mask and a sensor is taped to one of his fingers.

The wait is awfully long. I keep asking the desk when the surgeon will be ready. First, it is scheduled for 6:30. Then it becomes “in another 30 to 40 minutes.”

Finally, at 7:30 a team shows up to wheel Kyle to the surgery floor. I trail behind the bed tightly, feeling rather upbeat. I have been prepared for the worst since Dr. Yanik’s consultation three weeks ago. Dr. Cooke’s recent report paints an even gloomier picture. We will soon know what he has.

When we reach a certain line on the floor, I am asked not to follow. Then I say to my son: “You will be all right, Kyle. Trust in Jesus.”

“Mr. Wu, the surgery went well,” the surgeon wakes me up from a snooze in front of the TV in the waiting room. Half dazed, I stumble toward to meet the doctor. He continues in a terse manner, “The liver looked very abnormal. The pathologist will give you the results.”

“Is there a reason for me to stay tonight?”

“No, your son is fully sedated. He will be kept that way.”

## ***32 - Death, Where Is Your Sting?***

The telephone ring wakes me up from a deep sleep. Sue grabs it quickly. It is Friday morning, around 5. My heart pounds my chest like a punching bag.

“Hello... Yes, this is Kyle’s mom...Oh, he is conscious...He wants his Pokemon cards...I’ll bring them in the morning...Shouldn’t he be sedated?...”

I am relieved that he still has his mind. I pray to God right then: Please heal him or take him quietly.

Sue calls me in my office half an hour before lunch. “Kyle looks so peaceful. This is the best he has been for a long time,” my wife tells me in an almost angelic voice. For a brief moment, I the possibility of a miracle flashes across my mind.

Then she dashes my hope by saying, “The nurses say that he can hear us but cannot show it. His skin looks so good...” It is as if my wife, the mother, were describing a sleeping cherubim. I can almost hear the tinkling of the heavenly bells. Please don’t stop, please, please...

“Hello, are you there?” Sue snaps me out of my trance. I suddenly realize that my wife is at peace. She is not suffering with her son anymore.

“Yes, I plan to leave work a little early...around 3:30 so that I can keep him company after you leave.”

As I walk up to the 5<sup>th</sup> floor room, through the window, I can see Sue sitting in a rocking chair reading. I push the door open to announce my presence to my boy who is lying still with his eyes closed. There are literally 6 or 7 I.V. and other liquid lines connected to him. Indeed, Kyle looks so tranquilly. Strangely, at that instant, I wish I could say to him, “Wake up Kyle! I know you are playing Opossum.” Can you do it one more time for the old time’s sake, my son?

I enter the room after donning the vinyl gown and a quick hand wash. “Kyle, Dad is here. I hope you can hear me. You will be all right. In case you did not hear...both Michigan and Michigan State won last night. Doesn’t that make you feel good? I know the nurses are doing everything they can to make you comfortable...” I begin to choke up as the monologue continues but manage to stop in time before it gets worse.

Sue and I decide to chat outside the room. “I turned the TV on so that he can still hear the cartoons...They won’t have the results for a couple days...His blood pressure seems to go up slightly when I talk to him...He should be O.K. here without us overnight...” Sue starts to fill me in.

Again, Dr. Ferrara finds me in the ICU conference room. This time I am studying German. Sue

has left to deliver newspaper--her diversion for the last year. It is Saturday afternoon. He closes the door behind him and then sits down next to me.

In a calm and gentle voice, he says, "We got the lab report. It is not good: the CMV, Cytomegalovirus is spreading through out his organs. He is already on Gancyclovir, and I do not know what else that I can give him. But I will check with the infectious disease doctor to see if he has something."

I close my eyes briefly to let it sink in.

"How much time does Kyle have?" I ask after a swallow.

"It is hard to say, but my guess is that it could be a couple of days without life support. I'd ask all of you to come to say good-bye to Kyle tomorrow."

After a pause, Dr. Ferrara goes on by saying, "Let me say this to you and Sue: You have been wonderful parents to Kyle. You have been calm and positive throughout. Kyle talks about his sisters and the dogs all the time. He is so proud of them..."

I call Sue right away to let her know. She has not started on her newspaper routes yet. We agree to be with Kyle after church Sunday as a family.

As I walk out of the ICU's double doors towards the elevator, I am burdened with a sense of resignation. Does the whole world care about what I am facing? I want to tell the folks waiting

for the elevator. But wait, what can they really say to a stranger? Would their sympathy make me feel better?

When I get back to the house, I run into Shila in the kitchen. "What has mom told you about Kyle?" I ask.

"I know already. So does Joyce. Mom has asked us to be prepared to say good-bye to Kyle," replies Shila, "When I saw you and mom sitting on the couch whispering the other day, I knew it was serious."

Then I announce to her, "I am going to write an obituary about Kyle and his short life with us. I hope I can finish it in time."

"I don't know what I'm going to do yet, but I'll think of something."

Knowing that my daughters are poised, I plop myself down in front of a computer. Should I write an article? It would sound too dry and take too long. How about a poem? That is it! But what title?

After struggling for about 8 lines, I find it difficult to continue as I flip back and forth between strong emotions and pulsing memories. There is no use. Finally, I decide to go to sleep with the help of a stress pill.

Unable to sleep, I go right back to the computer. This is what I end up at 5:00 a.m.:

*Short Life of My Son Kyle*

*I wanted a boy  
But we could not produce.  
Though daughters were a delight  
A son would be more complete.*

*You came to us a “terrible two”  
Full of mischief, resistance and anger too.  
We vowed to love, care, discipline as well  
Like all parents should continue to do.*

*Your first mom and dad had let you go  
To face the unknown all alone.  
Hope you never doubted that  
You became forever our own.*

*Kyle Reuben did not seem to have a ring  
No matter, that was your new name.  
Stubborn and impulsive, we soon learned  
Annoying sisters was your best game.*

*You wore Husky size and Youth Large tops  
Should football have been your sport?  
But coordination and speed were not there  
Not to mention quickness, endurance and such.*

*Reading surely was a drag  
But Goosebumps books you loved so.  
Soccer and baseball also tried  
Tae Kwon Do, piano, Scouting and more.*

*Adrenoleukodystrophy was a total shock  
Marrow transplant would be the only hope.  
Finding a donor took some time  
Mother of two was the chosen one.*

*Fishing and basketball you did most  
Right up to the transplant week.  
Saying good-byes to friends was tough*

*Held back a year was the choice.*

*Nausea, swelling, pain and much more  
You took it like no champion could.  
Prayers, cards and Beanie Babies too  
From people all over this wonderful land.*

*Came home after a 6-month stay  
Just before the Easter Day.  
Yellow ribbons swayed from the trees  
To the music of the coming Spring.*

*Recovery through Summer seemed awfully slow  
Down to clinic visits and fewer pills.  
Hope was building as time passed by  
But pneumonia broke the camel's back.*

*Into the hospital more and more  
Concerns mounted as findings grew.  
Drew Henson and Pokemon helped you cope  
Michael Jordan would be next.*

*Chances dwindled week by week  
Biopsies now had to be done.  
I prayed for a treatable cause  
But results came out otherwise.*

*On life support you were quickly put  
They said you could hear us still.  
We came to say a final good-bye  
Someday we will meet again.*

*Then you could say to Mom and Dad:  
I really appreciate the care I got.  
You released me to suffer no more  
Thank you over and over again.*

“Hello, this is Kyle’s mom,” Sue answers the phone a while after I crawl back into the bed,  
“...How low is his blood pressure? ...Oh yes, we now plan to be there as early as we can...”

“Len, are you awake? The ICU nurse thinks that Kyle might not last beyond today.”

“I can be ready very fast. Do you want me to go first?”

After some thought, Sue answers, “I think we can all be ready and get there soon.”

The sky looks gloomy. There isn't much light coming through the window. Standing together in the hospital room, I open up by saying, "Kyle, we are all here: Mom, Dad, Joyce and Shila. We want to good-bye to you. I hope you can hear us..."

At that point, we all start to quietly sob. Realizing that we can't continue like that, Sue suggests that we do it individually.

Joyce has made up a card whose cover displays an angel flying through the stars. The caption says: Kyle, I Love You!!! Flipping it open, I find these words:

***You are my brother and my angel. Fly high and don't let anyone pull you down. Now let God lead you home to the place where HE promised we would go when the time came. I will see you there. Don't be scared for you are going to a better place where there is no pain and no fear. You fought with all your soul, now it is time to rest. You will forever be in my heart, mind and soul. I love you more than any words can say!!! May your soul rest in peace with the One who created you.***

***Love Always and Forever,  
JKW***

When it is my turn to face my son alone in that dimly lit room, I can only mutter: "Mom and Dad are letting you go to be with Papaw and Jesus. We love you... We have been through so much together. You are a brave boy. Don't be afraid..."

As soon as I come out of the room, I post the poem I wrote on the door. Then I proceed to ask for a piece of paper to write these words to post as well: "Pain, where is your bite? Death, where is your sting? Because we know Jesus."

Pastor Tweedie shows up while I am still defiant. "Brian, nice of you to come! We are all here to say good-bye. See this?" I point to the writings on the door as he puts on the gown.

For about 10 minutes, Brian holds Kyle's left wrist and watches the vital sign monitor as he speaks an occasional word. After a prayer, he somberly leaves the room to go back to the ten o'clock service.

I walk out to the hallway where family waiting rooms are located to call my brother.

"Hi Jim, we just said good-bye to Kyle this morning. I'd suggest you, Jeanne, Brandon, Brent, mom and dad be prepared to catch a flight soon."

Surprised by the speed with which Kyle is deteriorating, Jim answers, "This is the Thanksgiving week. It might be difficult to get all of us on the same plane... The best thing for me to do is to see how many tickets I can get and I'll bring mom and dad with me. Jeannne, Brandon and Brent will most likely come a few days later. As soon as I hang up, I'll see what is available..."

Then I call Les Osenkowski to ask him to tell my department and my boss that I won't be coming in to work the next day.

Sue has left some time ago to take Shila home. It is late in the afternoon.

"I know both you and Sue have told me that you would not want to keep Kyle on life support. I just want to make sure that you have not changed your mind," Dr. Ferrara catches me alone in the conference again. This time he has brought an intern as a witness.

"I have not changed my mind, and, if Sue were here, I know she would say the same," I reassure the doctors, "But I am not comfortable with witnessing the removal of life support. And yet, my wife wants to be with Kyle when that happens."

In a chaplain-like voice, Dr. Ferrara acknowledges, "I fully understand. People are different -- some do and others can't. Of course, we will do it slowly and carefully to minimize any pain or discomfort. Let me say it again, you and Sue are such wonderful parents. I can tell from the way you have taken care of him. Kyle has been very fortunate. And, through it all, you have not raised your voice to our medical staff even once..."

I am touched by what appears to be Dr. Ferrara's farewell. His eyes appear to be glassy. I have always wondered if physicians have feelings. Now I know.

The silence in the room after their departure was both heavy and peaceful. There is no more oil in that lamp of hope which has been burning brightly for over a year. Sue, Joyce, Shila and I have done all we can, supported by church members, colleagues, neighbors, friends and the humanity here and afar.

I have to get up to move around, but I am startled by the sudden appearance of Marlene Glenn. She is one of Sue's closest friends. Our kids call her Aunt. When our eyes meet, we both break out sobbing. Our hug seems to go on forever.

"I'm so sorry, Lenny...I remember when I first met him...those ruby cheeks and the smiles...And, that time I took him and Patrick to a restaurant...Oh, I forget where...." Marlene's reminiscence continues without stopping.

"Sue should be back any minute now. She took Joyce and Shila home a while ago. Let me take you to see Kyle..."

I continue the conversation outside Kyle's room, "They are turning off the life support tonight, but I'll be home though. Sue is going to stay."

Just then, Sue walks up. Tears come down our faces once more.

Stretching out my trembling arms, I give Sue a hug before looking over toward my son through

the picture window one last time.

“I’m going home now. I’ll know he is gone when you come back.”

I wake up in bed around 2:00 but do not find Sue in bed. No, not yet -- Kyle must still be alive. I wake up again around 4:00. Still, no Sue. My boy must still be hanging in there.

I get up after the alarm. In pajamas, I open the back door to see if Sue’s van is in the garage. No, it is not there. Both Joyce and Shila are in the kitchen, having a chit-chat before leaving for school. So I join in for a light conversation.

Suddenly, I spot a note on the counter by the coffee machine. It reads, “Girls, Kyle passed away at 12:23 a.m.” But where is she?

Just then, we hear a faint voice from upstairs, “Please be quiet, I am trying to sleep in Kyle’s room.”

O Lord, it is over. Finally it is over. We all start to cry as I hug Shila first and then Joyce.

Within minutes, Sue comes down.

“Where is your van? How did you get back?”

“The women drove me home. They wouldn’t let me drive even though I could have,” says Sue in a normal voice, “Guess who stopped by at mid-night after their shift at the hospital? Danielle and Wendy Switala. They stayed with Roseanna Botorowicz, Michelle Beaker and me to continue the vigil to the very end. The nursing staff asked me if I wanted to crawl in the bed with Kyle. I said it might hurt him. After his passing though, I asked the nurse to lower the bed so that I could hug him and kiss him good-bye.”

I break down crying hard this time because of that maternal bond between a woman and a child. Where was Dad? Where was I? I hope you understand, Kyle, my son. My very own also.

### **33 - *Grieving***

“I have visited both funeral homes in Brighton yesterday and I feel more comfortable with...,” I proceed to let Sue know which one we should go with Monday morning. Sue agrees. I then call the funeral home to let them know I am coming.

Ever since I got up this morning, my chest has been tight. But as I open the Neon’s door, my collar bones begin to behave like a draw string in a laundry bag. My heart feels smothered. Panic sets in. Could it be a sign of a heart attack? I hurry back inside to take another stress pill, hoping that it would help. That feeling does not seem to want to go away until I meet James Sr. inside the funeral home. I suppose the funeral details provide the distraction needed.

We decide on Tuesday night and Wednesday for visitation. The service and burial will be held on Friday. Our church seems to be the best choice for all events because of its large size. There is ample parking. Sue and I then proceed to visit a couple of graveyards in Brighton. But we like

the intimacy of the township's historic Pleasant Valley Cemetery just a mile down the road from our house.

My brother Jim is flying in with my mom Monday night while the rest are coming with Jeanne the day of Thanksgiving. Brighton Argus, Ann Arbor News, churches, place of work, schools, hospital and friends are all notified. The arrangements just seem to fall in place.

Both Joyce and Shila start to dig through pictures and mementos for the memorial displays. I don't know when, but Shila somehow manages to write this poem:

*Kyle, you mean so much to me,  
But now it's too late for you to see.  
All the laughter we were going to share this coming year...  
It's hard to believe that you're no longer here.*

*I remember trying to play soccer on windy, autumn days...  
Struggling to see through the foggy haze.  
Even though I only knew you for a number of years,  
We shared tons of craziness, happiness and tears.*

*What you mean to me, no one will know...  
Because affection is what I do not show.  
I love you so much and will miss you always...  
And I will miss you each and every one of these days.*

*You touched so many lives, only a few that you knew,  
And, oh, how everyone will be missing you.  
You were courageous, brave and strong,  
You fought so hard, so long.*

*I love you, Kyle, yes, I do,  
From this day on, I'll be missing you.*

As Roseanna Bortorowicz suggested earlier, Joyce decides to make up a picture board with Shila's help. She then adds to it a poem on which two pictures of her brother are pasted – one before and one after the transplant. It reads:

*Kyle*

*You have been a part of my life for nine years,  
Nine wonderful years with wonderful memories.*

*Life won't be the same without you.*

*We will think of the good times, not the bad,  
We will remember your smiles, not the frowns.*

*A little guy with a big heart,  
Who is smart way beyond his years.*

*You have gone through so much pain,  
Now you can rest and feel nothing but joy.*

*You may not be here in flesh and blood,  
But you are in my heart, mind and soul.  
You will be with me always and forever.  
In my grief and in my joy,  
In life's good times and the bad.*

*You will never realize all those you have touched,  
All those that love you,  
All those who admire the strength  
One little boy had inside him.*

*You have fought a hard long battle,  
Now the battle is over;  
Now you can rest.  
I love you more than words could say.*

*JKW*

## **34 - A Surprise Phone Call**

I spot an opened envelope from Fairview University Hospital on my desk as I take off the pager used at work from my belt. It has been a while since we received anything from Minnesota. When I pull out the content, I realize that it contains the personal information about Kyle's donor. Sue must have read it already. In the quiet study, my heart pounds like a lone bass drum. More than a year's curiosity is about to end. There are only two sheets. The cover letter from Fairview reads:

*December 7, 1999*

*xxxxxxx  
xxxxxxx  
xxxxxxx*

*Dear Mr. And Mrs. Wu:*

*We have received the Consent to Release Personal Information from both you and Kyle's donor. I am enclosing a copy of the donor's release, which includes her... I will send a copy of your release to your donor as well.*

*I hope that your contact with the donor brings you both joy.*

*Sincerely,  
XXXXXXXX*

The name sounds German, but that would be her husband's. She is from Indiana. Where is Cynthiana? It should be in southern Indiana since in her last letter she mentioned that the school started for her daughter in mid-August. I wonder what her nationality is. Could she even be of Korean descent? Who knows? The data sheet seems to produce more questions than answers.

"Sue, what do you think? Should we call her?" I yell out for my wife.

Sue answers back by saying, "I have been thinking... We should wait till after the holidays. I don't think we should ruin their Christmas."

"All right, we'll wait then."

"The donor's husband called this morning. His name is Paul," Sue makes a surprise announcement as I step into our house after work. It is Thursday, Dec. 16, 1999, "I did not know who he was first until he said he is the donor's husband."

"What did you tell him?"

Sue continues to tell me the rest, "After I introduced myself as Kyle's mother, he enthusiastically asked how he was doing. I told him he passed away in the morning of Nov. 22. There was a dead silence. I started to cry. I was sure he did too. Since they had not heard from Kyle for a while, they had interpreted that to be good news. Then I asked where Cynthiana is. He told me it is just north of the Kentucky border, near Evansville. It all made sense because of his southern accent. He sounds like a friendly, nice guy. Let me show you the map where Cynthiana is..."

"Did you speak with Melissa?" I quickly break in.

"No, she was at work."

Like so many curious minds, I boldly ask, "Did you ask what her ethnic background is?"

My wife says, “No, I did not, but I did say that we would be in Tennessee and Kentucky before and after Christmas. And, we’d like to meet them. Then he said they are only two hours from Glasgow. He said he would ask Melissa to call me tomorrow to work out the details, but I told him I was thinking the Tuesdays after Christmas on our way back to Michigan.”

The conversation wakes up those inanimate words on the Consent to Release form. We are secrete pen pals no more! Like never before there is that sudden feeling of kinship. Why, certainly! Kyle would have carried in him the same exact blood type as Melissa’s for the rest of his life had he lived. O Lord, how much more wonderful it could have been...

### ***35 - Meeting Melissa***

We are running half an hour late on Green River Road in Evansville, Indiana, searching for Red Lobster, the restaurant picked for our dramatic meeting. On the way from Kentucky, I must have flipped through hundreds of faces in my mind, trying to guess what Paul and Melissa might look like. We finally pull into the parking lot after a query at a gas station.

I hurriedly stack the presents in Shila’s arms while Joyce takes my still camera and video bags. After grabbing the photo albums and my compact camera, we quickly shuffle toward the entrance. As soon as I push the outside door open, a petite blond stranger standing inside asks if we are looking for the Hopf’s. I respond with a short “Yes.” Momentarily, I mistake her for the hostess.

“I am Melissa. Are you Kyle’s parents?” asks the pretty young woman who could pass for Michelle Pfeifer’s sister.

My heart begins to race as our eyes are glued to one another’s. The brief eye contact gives way to an unsolicited firm embrace as my mind flips back and forth between elation and lamentation.

Leading Sue on with the rest of us trailing, she says, “Follow me. Paul and our girls are waiting in the back of the restaurant.”

After a round of introductions, my wife hands Ashley and Kiley their gifts. Then she presents a professionally wrapped box from Brighton’s Somewhere In Time to Melissa which contains a collection series angel figurine holding the hand of a boy and a girl. The moment when the figurine emerges from the box is both symbolic and real: Melissa, you gave a part of you to my son so that he would have a fighting chance. My son, how I wish you could be here to be held by your earthly angel, even just for a fleeting moment. Someday, yes, someday Kyle, you can tell me how appreciative you are.

I spent two nights to select and scan the materials on the computer to stuff the album whose cover is decorated with butterflies. I picked the design because what they symbolize: transformation. Now seems to be the time to give it.

“Paul and Melissa, here is an album we want you to keep. It tells Kyle’s story with pictures and newspaper clippings, articles, letters and poems. It starts with the fund raising and ends with his funeral, covering a period of almost two years...See the kids at school making Beadie Babies to

raise money... Here is one from Brighton Argus announcing that a donor is found...Ah, this is how Kyle looked after the transplant...Another one of Kyle and me sent from the Tribune in Minneapolis to the Ann Arbor News...There is a copy of the book I have been writing, but the last chapter is happening right now...I’ll give you a copy of the finished version. I hope it will be soon...”

Sitting next to him as we continue to talk, I have noticed several times that Paul has tears in his eyes.

“Here is a baseball signed by Don Mattingly of the New York Yankees for Kyle,” Paul extends his right arm toward Sue and me, cupping the encased autographed treasure, “We were really looking forward to presenting it to Kyle, but ....”

There seems to be a brief moment of hesitation in his speech, but he proceeds with pride to tell us that Don is from the local area and he hangs around during off-season.

“Kyle, my son, I wish God would send you back just to hold it in your hand, showing that inimitable grin of yours one more time,” I find myself lamenting again.

Personal discoveries about one another pile up rapidly at the round lunch table. I suddenly pop the question, “How did you become a marrow donor, Melissa, and what was it like to go through the procedure?”

Then she begins to tell her story, “I had to go to Indianapolis last October. It is about 3 hours drive. I was anesthetized before they tapped into the back of my pelvic bones at three places...I didn’t feel a thing...I would do it again in a heart beat...How I registered as a donor...You see, there was a donor drive here in the summer for a child in our community...She died before a match was found...I was contacted in August...and again in September...It happened so fast...Of course, I did not know for whom my marrow was needed...”

“Kyle is buried a mile away from our house,” I try to think of more to tell her.

“I’d like to visit his grave,” says Melissa without hesitation.

Touched by her sincerity, Sue invites them to come to Brighton to stay with us. After all, we are now related in a miraculous way.