

MPD VOICE

Voice of the Myeloproliferative Disorders Community

Life Before, During and After a Stem Cell Transplant for MF

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Published quarterly by
 CMPD Education Foundation
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 Scottsdale, AZ 85261
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From the President

Joyce Niblack



This issue of MPD VOICE focuses on the transplant experience of MF patient Larry Hirsch and his wife, Iva. Larry and Iva are attorneys with their own law firm in Phoenix, Arizona.

Their attitude and spirit leading up to, during and after Larry's successful transplant are remarkable. I am so glad they were willing to share their story with others. I encourage anyone facing transplant to take Larry up on his offer to talk to you. His contact information is at the end of his story.

The decision to have a bone marrow or stem cell transplant is a difficult one. At the February 2007 Mayo/CMPD Education Foundation MPD conference, Dr. Tefferi identified 5 criteria that indicate transplant may be appropriate. To make sure I had them right, I asked him for a quote for this newsletter. He said:

1. Platelet count below 100,000 micL
2. Hemoglobin below 10 g/dL
3. Leukocyte count either above 30,000 or below 4,000 micL
4. Monocyte count above 1000 micL
5. High-risk cytogenetic abnormality such as complex chromosomal changes"

Dr. Tefferi said if two or more of these are present, it is time to talk to Dr. Deeg about transplant.

A reminder that Dr. Silver's MPD November 7, 2007 MPD patient symposium is rapidly approaching. The link for registration information is at www.mpdinfo.org

Patient-Doctor Sharing

Larry 2.0

Larry Hirsch



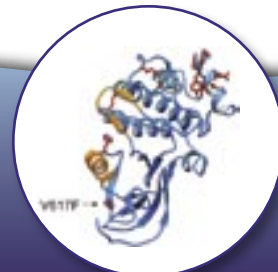
Larry and Iva at the Niblack's on 10/10/07

I was diagnosed with myelofibrosis in September, 2004 after a routine physical showed a very low red cell count. I flew to New York for a consult with Dr. Richard Silver, who confirmed the diagnosis. I began treatment at Mayo-Scottsdale almost immediately. My spleen was enlarged and I was placed on a drug protocol of thalidomide and prednisone. I remained on that protocol for about a year and a half until I volunteered to participate in a revlimid drug study, which was unsuccessful.

My spleen continued to grow and my energy levels were diminishing. My quality of life was definitely on the decline. I had met with Dr. Deeg at the Seattle Cancer Care Alliance in November, 2004 and decided that it was time to visit him again. My doctor at Mayo-John Camoriano-concurred and my wife and I traveled to Seattle in December, 2006 to further explore the idea of a bone marrow transplant.

(continued next page)

1. Mayo Clinic, Scottsdale, Arizona
2. Fred Hutchinson Cancer Research Center, Seattle, Washington
3. Harvard Institutes of Medicine, Boston, Massachusetts
4. Mayo Clinic, Rochester, Minnesota
5. Mayo Clinic, Rochester, Minnesota
6. MD Anderson Cancer Center, Houston, Texas



When I first visited Seattle, I was told that I had a 70% chance of a 15 year survival. That did not seem like good odds at the time. I had just started treatment and was hopeful that a drug treatment would become available before my fibrosis became too severe. By December, 2006, the 70% odds seemed a lot better, as the revlimid did me no good and there did not seem to be a drug treatment coming any time soon. I felt that my window of opportunity was beginning to close and that it was time to do something. I had hoped to wait until after the summer of 2007, but circumstances dictated a more accelerated course of treatment. In February, 2007 I began to experience problems in my breathing, as my spleen was beginning to push against my diaphragm and I could not get a good breath. It was time to get going on the transplant.

We called the SCCA and told them that I wanted to go there as soon as possible to start the process. They were able to quickly find a match and we left for Seattle on Easter Sunday, 2007. I began treatment at the Hutch (the local nickname for the center, which is called the Fred Hutchinson Cancer Research Center) the following Tuesday.

Before we left Phoenix, I had the chance to talk to two people who had gone through the transplant process. I learned that each experience is different but that a strong mental attitude is critically important. I did some research into Jewish healing principals and read articles about other people's experiences with transplants and chemotherapy. I felt that I was in good shape physically and would be able to withstand the rigors of the chemotherapy and that my mental health was good. Iva, my wife, encouraged me to see yourself on the other side. In other words, I should focus on being better and not obsess about the process I was about to experience.

I entered the University of Washington hospital on Monday, May 7, and began chemotherapy almost immediately. The treatment protocol called for 6 days of

chemo followed by a day off and then the transplant. I really did not begin to feel the effects of the chemo for several days. However, by the time of the transplant I was beginning to feel sick-my throat hurt and nothing stayed in my stomach for very long-it seemed that more was going out than was going in! I was able to continue to exercise during the chemo process and kept walking every day even when I could not ride an exercise bicycle any longer.

What I had learned from my pre-transplant research was that it was important to the mental health of the patient to continue to do things that made me feel like myself and try to make the hospital environment as familiar as possible. For me, that meant getting up every morning and getting some exercise. That is something I have done for many years and it is necessary for both my physical and mental well being. I would walk the halls of the hospital wing every morning, listening to music on my i-pod. I also would get dressed into my own clothes-something else that I considered important for my mental health. I also decorated the walls of the hospital room with pictures of my children and art from my home and put up a mezuzah-a Jewish religious symbol which appears on the front door of Jewish homes-on the door to the room. It certainly wasn't home, but I felt less like a patient and more like a visitor. I also spent time every day writing emails, reading emails, reading the newspaper, looking at news on line, doing the daily New York Times crossword puzzle and reading. All of these things helped to keep me mentally sharp and distracted me from whatever physical circumstances I found to be uncomfortable. There were days when I could barely read a few pages-the chemo made it very hard for me to focus for very long. Even watching a television show was difficult-I simply had no attention span.

The transplant itself is a fairly simple event-it is simple a transfusion of stem cells from the donor. The process is pretty remarkable. The donor receives

injections for 5 days which stimulate stem cell production. On the 6th day the donor goes to his or her local hospital where blood is taken from the donor. The stem cells, which have overflowed from the marrow to the blood system, are separated from the regular blood. The blood is then returned to the donor and the stem cells sent to me. I was extremely fortunate to have a perfect 10/10 match. It certainly helped in the recovery process. The transplant took place at 2:00 in the morning. A bag of stem cells was brought into my room. Before it was hooked up to my iv pole, my nurse placed the bag on my chest. I have thought long and often about the fact that I had the opportunity to "visit" with my new stem cells. I still think about it. It was a moving and deeply spiritual experience.

After transplant, I had to wait for my white cell count to get to zero (from the effects of the drugs). Once the count got to zero, it was time to wait and see if the new stem cells would engraft and begin to grow new white cells in my marrow. That process takes several weeks. During that time, my white count was zero-I had no immunities. Any stray germ or virus could cause major problems, if not death. We waited (not so patiently) and around day 17 after transplant my blood count showed growth of new white cells. Once the white cells started to come in, I could look forward to leaving the hospital.

The period of time between transplant and the introduction of new white cells was difficult and extremely uncomfortable. As a result of the chemo, I developed mucositis-the bad sore throat and pain in my stomach and bowels. The pain in my throat became so severe that I could not eat solid food and could only drink liquid if I pumped myself up with morphine before I tried to drink. I did not want to go on iv feeding and iv medications-I wanted to stay on real food as much as possible. Going on iv would extend my stay in the hospital, something that I did not want to do. They told me that I was the first unrelated third party donor transplant patient who had not gone to

iv feeding at some time in the process. I cannot emphasize how much mental toughness plays a part in the recovery. I would simply visualize myself in one of my favorite settings-sitting with Iva on our porch in Flagstaff drinking coffee on a Sunday morning-and remember that the transplant was a means to that end.

Finally, after a total of 31 days, I was permitted to leave the hospital. I had been in the hospital for 22 days after transplant, which is about average for unrelated third party donor transplant recipients. I was far from well, but was considered out of immediate danger. My white cell count was about 1,000 (1.0) and my neutrophil count was 500 (.5) which was indicative of engraftment-that the transplant had taken root and was successful. I was still then and am still today at risk for infection and illness. I was advised to avoid crowds, to not shake hands with people or embrace them unless they were healthy and had washed their hands, to limit my diet and take other precautions against illness. I am still taking immune suppressant drugs and will be on them until at least the middle of November.

The hardest part of the experience for us was the tedium of the post hospital recovery period. I was still weak and tired. There was a lot of down time and not a lot that I could do. We could not go places where there would be crowds, since my immune system was almost non-existent. We could go to movies, but only if the theater was not very crowded. We could go to a restaurant, but, again, only if it was at an off hour or we could get a secluded table. I could go to the mall, but only if it was not crowded. I needed to nap almost every day. I was at the clinic daily for quite a while and was always there at least 3 or 4 days a week for lab work or for picking up drugs. I had to have iv treatments for hydration or magnesium almost every day. Although we could do that at home, it was still part of a not so pleasant routine. Time went by slowly. We were simply not properly prepared for the slow pace of recovery.

It would have been impossible for me to get through this experience without the love, support and help of my wife and best friend, Iva. She had the difficult task of being my "care giver." She was in charge of my day to day care once I left the hospital. Before entering the hospital, a "Hickman" catheter was inserted into my chest. The catheter becomes the vessel through which blood products are removed and infused and medication is infused. The procedure would have been much more difficult to endure without the "Hickman" line. However, the line required daily cleaning both on the outside and by clearing the lines with saline and heparin. Additionally, Iva had to "hook me up" to iv hydration bags and magnesium bags almost every day from the time I left the hospital (June 6) until the day we left Seattle (August 14). Iva was (and is) my cheerleader when I am down and my governor when I want to do more than I should. She has taken very good care of me-I have not even had a runny nose or a sniffle since leaving the hospital. The role of the care giver is challenging and I could not have done this without Iva's support and love.

I was one of the very fortunate transplant recipients. I have suffered no effects of graft versus host disease (GVHD), which is the body's reaction to and possible rejection of the new immune system. Since I have had no GVHD I have been able to stop taking steroids and am tapering off the anti rejection drugs. Once I am no longer taking those drugs, I will be able to travel more freely, eat out without food restrictions, be able to drink alcohol and in most ways resume a more normal life. I have to return to Seattle for follow up visits every year for five years. I will get new inoculations in Seattle next April-since my old immune system was destroyed and my new stem cells have no built-in immunities, I am at risk for all diseases for which I was previously inoculated. I can never get inoculated with a live virus, as my immune system will always be impaired. I will never be able to travel to certain third world countries which require certain inoculations. I have a higher risk

of skin and mouth cancer than does the general population. However, I have my life back. I am more than happy with the trade-off.

A bone marrow/stem cell transplant is not for everyone. I am 55 years old and in otherwise good health. I had no secondary illnesses, such as diabetes, which created an additional health risk. My heart, lungs, kidneys and liver were in good shape. I was a good candidate for a successful transplant.

My best advise for those who are contemplating such a procedure is to act before the disease causes new problems. My fibrosis had not yet spread to my liver or kidneys or lungs. I was in good physical shape. I had the time to become emotionally and mentally ready for the challenges of the chemo and the hospitalization. What I was not prepared for and for which I am still facing challenges is the drudgery and the slow pace of the recovery. My pre-transplant fibrosis was high-somewhere between 3 and 4-and my spleen was of gothic proportions (it is still large but is shrinking). My red cell count is still low and I am still transfusion dependent. However, the time period between transfusions is growing and my platelet count has begun to rise and is now in the 60,000 range. It was in the 30s when we left Seattle six weeks ago. I was told that my red count would come in but would come in slowly and that it would be many more months before I was at a normal level. I hope to be off transfusions by Thanksgiving and to a normal level by the late Winter/early Spring of 2008. Patience is not my long suit and I am frustrated that I cannot do all the things that I used to be able to do, but I am learning to be satisfied with what I can do now and be happy that I am able to do more each day. I still nap most days but am able to regularly exercise and my mind is becoming sharper again.

I am happy to be of assistance to anyone contemplating a transplant. I think that I did as well as I have done due to several factors. The first and most important was

the ever present support of my wife and care giver, Iva. I could not have gotten through the illness or the transplant without her love and support. I am forever grateful to her. We are blessed with wonderful friends and family who stood by us and gave us constant support from afar. Many came to visit in Seattle (leaving Phoenix for Seattle in the summer is a good deal!) They helped keep our spirits up when we were running out of gas. We had time to learn and get prepared. I had almost three years to think about what I wanted to do. I was able to read and talk to others. I pretty much knew what to expect. I was very lucky and my experience was far less challenging than that of many others. Each transplant and each experience is different. The more you can learn about the process and the more you can physically, mentally and emotionally prepare for the experience, the more likely you are to at least not panic when something happens. I knew to expect pain in my throat and other problems. The nurses told me what to expect and how I would feel. When what they told me to expect actually happened, I was ready for it and knew that I would get through it. If anyone wishes to contact me to discuss my experience or to discuss their situation, please contact me at lhirsch@hirschlaw.net and I will respond...



Larry, Iva & Larry's huge spleen-June, 2007



Larry October 10, 2007

MY CAREGIVER EXPERIENCE

by Iva S. Hirsch

My husband, Larry, was diagnosed with Myelofibrosis in September, 2004. Being a caregiver started on that day in the office of the hematologist when we received the diagnosis. Being a caregiver meant that in spite of my shock and my own sadness and anxiety over the diagnosis, that I had to be supportive of my husband. There needed to be at least one clear head. That often meant engaging in a juggling act of emotions and rational decision making in order to make best possible treatment decisions. Early on, I had unilaterally come to the conclusion that the only alternative was for Larry to opt for an unrelated donor bone marrow transplant. My frustration was in watching Larry continue to deteriorate from the disease. The clock ticked away, while he struggled with the decision to assume the risks associated with an unrelated donor transplant versus the quality of life he knew he could obtain from treatment of the symptoms.

In June, 2006, Larry participated in a clinical trial for Revlimid. Instead of a miracle, which we had hoped for, it was a nightmare. Larry's platelet count, which had to be 100,000 to be eligible for the study had declined so dramatically, that his doctor withdrew him from the study in August. Larry was very upset and wanted to see the clinical trial through. Around Labor Day, a friend connected us with a couple who were planning to go to SCCA in October. They agreed that we could telephone them to talk about Seattle and the process. The day we planned to call them, we read in the newspaper that Susan Butcher, the woman who had won the Iditarod, had died due to complications from her transplant at Seattle Cancer Care Alliance (SCCA). We decided to wait to telephone them because we didn't know them, and we didn't know how they would react if they had read the article. When we did speak, they were very gracious, given the fact they were going through their own issues with the husband's cancer. The husband was a prominent

ophthalmologist in Phoenix. He had had cancer and had taken chemotherapy treatments locally while continuing to practice medicine. He told me that "his middle name used to be Mr. Convenience" and that he was sorry that he waited so long before making the decision to get a "mini" transplant in Seattle. He urged us not to wait too long to make the decision to go to Seattle. We arranged to meet them for coffee in Seattle when we had our appointment to see Dr. Deeg in December. Unfortunately, the wife called us two weeks before we were supposed to meet to tell us that she and her husband were coming home to Hospice care. He past away in Phoenix before we even got to meet him in person. His widow was an angel. Within a few weeks after his death, we talked on the telephone and had dinner with her. Even in her grief, she was gracious enough to share her experiences with us. She encouraged us to go to SCCA, and told us that her husband had had a successful transplant and a perfect match, but the tumor had come back faster than the engraftment had taken.

After my husband's spleen became so large that he was having trouble breathing, the decision was made. We decided to go to Seattle Cancer Care Alliance. Our research concluded that they had more experience with transplanting myelofibrosis patients than any other facility in the U.S. I also liked what I saw, and once we consulted with Dr. Deeg, in December, 2006, I had every faith in the medical care, the facility, and in the process. Once the final decision to have the transplant was made, Larry became very inwardly focused in order to mentally, physically and spiritually prepare for the transplant process. It was up to me to address the more mundane issues, such as: Where are we going to live? What are we going to do for transportation? Who is going to watch the house? Who is going to watch the business? Who is going to pay the bills? How are we going to address the financial issues of no income and continuing overhead for four or five months?

We knew that SCCA required that the patient arrive in Seattle with a caregiver prepared to stay with the patient during the entire stay, which at minimum is pretransplant medical testing, the hospitalization and a minimum of 90 days post transplant. Initially, we thought that I could travel back to Phoenix for a couple of days when Larry got out of the hospital, assuming that he had no complications, and have his close friend cover for me. Once we arrived in Seattle, it was clear, that barring a true family emergency, I would not be able to travel back to Phoenix.

Both of us are attorneys and together we own a small law firm. Some of the logistics of putting our life on hold were mind boggling, but it was clear to us that he should go to Seattle Cancer Care Alliance to get the transplant at any cost. In retrospect, we both agree that being removed from our daily routine and the expectations of us associated with our daily routine and obligations was a good thing. It is easy to explain that you are a caregiver and can't help your client out or do X if you are two thousand miles away in another state. We both agree that the pressures of our law practice would not have been as removed if we had stayed locally for the procedure. It would be hard to explain to a judge, a client or an employer that you have to go to the hospital for eight hours a day. They wouldn't necessarily understand why you can't prepare a document or attend a court hearing in your "spare time."

One of our friends is a social worker for the kidney transplant unit at Phoenix Children's Hospital. She had warned me against doing any work at all while I was away. As it was, I kept some of my clients and continued to telecommute approximately two hours a day. What would be normal professional stress multiplies geometrically when you are a caregiver. My cell phone also inevitably would be ringing at the most inopportune times. There were times when both cell phones and the house phone in the apartment were all ringing simultaneously. My nineteen year old

daughter came to visit and she even told me she couldn't believe that my cell phone rang so much! If you are a caregiver and have a high stress profession, I do not recommend what I did!!!

During the pretransplant medical testing, as the designated Caregiver, I drove Larry to the clinic, met with his team, and spent a lot of time reading at the clinic and drinking lattes at the clinic's cafeteria. I was also required to take classes designed for the caregiver and the patient. These classes included how to care for the Hickman Catheter and how to administer infusions at home, how to use the portable pump for infusions, dietary restrictions and food preparation procedures for immunosuppressed transplant patients, kitchen cleanliness, and restrictions on daily living and lifestyle, such as not having fresh flowers, silk plants, or plants in the home, not touching animals, reptiles or birds, and changing the patient's towels and clothing daily. How well you follow these rules can make the difference between your loved one being hospitalized for an infection or living at home during the period that they are immunosuppressed. I took these classes very seriously, as does SCCA.

We made the decision not to stay at Pete Gross House (the SCCA-owned apartments) with the other bone marrow transplant patients and their families. Fortunately, we did not need to base our decision on strictly financial considerations. We decided that the best way for us to tackle this challenge was for us to live as normal a life as possible. We felt that any support system we developed at Pete Gross house would be outweighed by the emotional drain it would be on us to give support to others. I also felt it was important to have a nice cheerful apartment with lots of windows to compensate for the dreary Seattle spring. Our emotional support system was our friends and family. I actually visited the Pete Gross House a couple of times, and quite frankly it was no cleaner than our apartment building. SCCA recommends that you live no more than

a twenty minute drive from the clinic in the height of rush hour. Seattle traffic is a nightmare. We lived less than two miles from the clinic and some times it took us fifteen minute to drive there due to traffic and construction.

My role changed when Larry was hospitalized. Larry was hospitalized for thirty-one days. We had expected a three to four week stay, but they won't release the patient from the hospital until certain levels of white blood cells and neutrophils are met, and the patient can eat and take medications orally. I had thought that I would have to be more vigilant at the hospital, but I was very impressed with the competency of the nursing staff at University of Washington Medical Center, and Larry was clear headed enough to meet with the doctors in the morning on his own. Because Larry was able to meet with the doctors himself and there were no complications where I felt I needed to be a part of those daily early morning doctor's visits, I spent my mornings going through my emails, returning calls and telephonically managing life at my house and office in Phoenix. I tried to take a walk or work out in the apartment's gym as often as I could. I also spent a lot of time collection my receipts and mailing them to the insurance company for reimbursement. Even so, I usually spent six to eight hours per day at the hospital.

Visitors are not allowed to use the rest room in the patient's room, as the nursing staff is constantly checking the patient's output to be sure that there is no dehydration. As a result, there is a family lounge on the floor which is a room with a telephone, television, refrigerator, coffee and tea, toilet and shower. Patients are not allowed in the family lounge nor are they allowed in other patients' rooms due to the great risk of infection. You are not allowed to bring food into the patient's room and bring it out again unless it remains sealed. My typical routine was to go up to the eighth floor, use the hand sanitizer, mark my lunch and/or dinner with the patient's name, room number and date and place it into the communal

refrigerator, and use the hand sanitizer again. Then I would go visit Larry in his room.

Visitors are also not allowed to come to the hospital to visit if they are sick, or contagious. I had a sinus infection while Larry was in the hospital. Fortunately, my sister was visiting and the day I was too sick to visit, I dropped her off at the hospital and picked her up and she spent the day with Larry.

When friends came to visit, I used that opportunity to go shopping and get my hair cut and pedicures. I only slept at the hospital the night that he received his stem cell transplant through a transfusion. We had a healing service and said prayers earlier in the day and this was the most important day in the beginning of his life going forward. Otherwise, because the process is such a long haul, I took care to save my energy for the task of caregiving after his release from the hospital.

There was also a very dark side to the hospital visits. Every time I need to use the rest room, I had to go the family lounge on the eighth floor. Inevitably, a caregiver or relative of another patient on the floor would engage you in conversation. Every story that I heard made me count my blessings that we had made the decision to get the transplant before the myelofibrosis morphed into Acute Myeloid Leukemia. It was very depressing. Every person in the family lounge was living a life and death drama with their owned loved one which all seemed much worse than mine. After a couple of weeks, and the deaths of a couple of patients whom we had met at the clinic, as a matter of self preservation, I found a rest room in the cancer ward to use and avoided the family lounge as much as possible. I realized that I needed all of my energy to maintain the emotional stamina to be there for my husband, and there wasn't a lot left to give. I know that sounds very cold and selfish, but I ended up giving the same counsel to another caregiver when one of her friends from Pete Gross House lost her husband. As it

was, one of the patients that we became friends with passed away shortly after his departure from SCCA. This is not a process for the fainted hearted from either the patient's perspective or the caregiver's perspective.

When Larry started getting a back ache around the third week, I went to Costco and bought him a mattress pad with the high density foam insert for his hospital bed. This was a godsend for him because he had so much back and shoulder pain that the doctors had made a referral for him to the physical therapist. Actually, placing the box on a wheelchair in the garage and wheeling it up to the eighth floor was one of the highlights of my visits to the hospital.

When Larry finally got out of the hospital my responsibilities increased from support system and wife to include "caregiver." After spending thirty-one days in the hospital, Larry was more than ready to get out. After all, how many times could we watch the Montlake bridge go up and down from his window? When he was initially release from the hospital, he had over twenty pills to take daily at various intervals. When we first arrived at SCCA they provided us with a pill organizer with 28 slots- four for each day. We both rolled our eyes, but soon realized that there was a method to this madness. The first thing we did when we got back to our apartment was go through his medication list and load the pill organizer. This was definitely a two person operation and we developed a routine where we would fill it together every Friday after we had visited the doctor at the clinic.

After his release from the hospital, Larry had to go to the clinic seven days per week for blood tests. Larry continued to go to the clinic to get blood tests for several weeks after he was released from the clinic. Even after he "graduated" to three times per week for blood tests, I do not think there was ever a week when he was there less than five times. Even so we were fortunate, as we were told it is common to develop infections and be

rehospitalized during the 90 days post transplant.

I had to administer IV hydration and IV magnesium to him to counter act the side effects of the anti rejection drug which he was receiving. He had a portable pump which fit into a back pack so we could go out while he was infusing. In Seattle, nobody blinks an eye when they see someone walking around with a back pack with tubing running from it to the chest. We had to time the infusions so we could do things and still get him home to disconnect the bag and clean his Hickman line when the infusion was finished. Larry was lucky. Many of the other patients we met needed infusions of antibiotics, or insulin as high blood sugar is also a side effect of the drugs.

Although we were well prepared for his stay in the hospital, we were not emotionally prepared for the tedium of the ninety day stay in Seattle after the transplant. I was constantly cleaning and sanitizing the toilets, sinks, and kitchen area. I was washing his towels and clothing daily in hot water. The clinic has the patient on a very short leash. I always kept my cell phone on and always answered it. We were there almost daily, sometimes more than once per day, changing medications, picking up supplies, hydration, magnesium bags, or filling prescriptions. Larry also was still transfusion dependent and every two units of red blood product meant four and one-half hours in the infusion area on the fifth floor. Fortunately, there are televisions in the infusion bays and ESPN and his cell phone provided him with enough entertainment that I could drop him off, go grocery shopping, and pick him up later in the day.

We learned that exposure to the sun could trigger graft versus host. We also found out that because of the significant exposure to chemotherapy as part of the conditioning for the transplant, Larry is at a higher risk of skin cancer. One of our first field trips after Larry left the hospital was to REI where we bought him a good hat with a wide brim, and SPF 30

overshirts to wear when he went out. Later, we found a nice men's hat store and bought Larry a few more fashionable hats, since these will now become a part of his life.

Before the transplant, the clinic gave us a triage sheet to keep in our home along with a patient and caregiver handbook. I hung the triage sheet on the refrigerator because it told you when to call the clinic and when to call 911. I referred to the handbook constantly. My only complaint was that it was geared more to cancer patients as opposed to MF patients, so some of the information which I took as gospel, turned out to be not applicable to MF patients.

I also became the diet and hygiene police and informant; roles which I did not enjoy. I made the final determination as to whether we could eat at a given restaurant or Larry could order a certain food. On clinic days, I helped myself to the prepackaged ketchup and mustard and kept them in my purse so if Larry ordered a hamburger on a plain bun and french fries, I had the condiments (Larry was not and is still not allowed to eat fresh fruit and vegetables not prepared by me. Nor is he allowed to use a common bottle of ketchup or mustard on the table in the restaurant). This was a role that I did not relish!!! It was necessary however, because someone had to be able to say "no." Larry was to avoid crowds at all costs due to his suppressed immune system. This was a source of frustration for both of us as we had to avoid concerts, plays, museums, ferries, and any other situation where there was a crowd. We usually ate home and stayed home on Friday and Saturday nights, went to the movies mid week, and sat far away from the other patrons. We both were really excited when his white blood cell count was high enough to get clearance to cautiously attend a Mariners game by coming late, leaving early, and avoiding the public rest room.

The worst was when he would have bad stomach cramping and diarrhea. We were never sure if it was graft versus host, an

infection, or the side effect of massive amounts of magnesium. We thought it was the side effect of the magnesium, but how could we be sure? There were times when we disagreed about whether we should call the clinic about the symptoms which he was experiencing. I wanted to call the clinic. He wouldn't want me to call the clinic because he didn't want to go back to the clinic to endure whatever new trick they had up their sleeve. I would call (of course), over his objection, and the triage nurse at the clinic could hear him complaining in the back ground. The nurses understood that at times the patients were running out of patience for being a patient!

We looked forward to leaving Seattle and coming home after being up there for so long. I was counting the days. When our team told us we could leave about a week sooner than we thought, we were elated. Our team decided that Larry should have a platelet transfusion the day prior to flying back to Phoenix. Larry scheduled it for 8:00 a.m., so he could do his magnesium infusion afterwards and be free to spend an afternoon with me walking around the city, after dropping off our car. We finished his IV magnesium infusion around noon. We were in the car on the way to meet the trucker who was going to transport our car back to Phoenix, when the phone rang. It was the clinic and they wanted to give Larry a hemoglobin transfusion before we left the next day. He needed to get cross matched as soon as possible so they could order the blood. Larry was had had enough and wanted nothing to do with another four and one half hours at the clinic on his last day in Seattle. I ended up cashing in a huge stockpile of "chits" that I had built up with him in Seattle to get him to take the transfusion that Monday afternoon. It turned into an all afternoon and all evening affair. After getting cross matched at the clinic, we had to go to University of Washington Medical Center, because the clinic infusion bays were all booked that day. Our last dinner in Seattle was carry-out pizza that we had delivered to the hospital while he had his transfusion. I ordered several desserts

from the hospital menu and ate them all! We ended up taking a cab home from the hospital at 10:00 p.m. that evening. Our last day in Seattle was spent by us with Larry having two transfusions and an IV infusion of magnesium. It was not fun, but typical of the unpredictability of every day there.

Larry had a superb result from the transplant and we are very thankful. However, nothing is perfect. Larry had to leave Seattle after ninety days with his Hickman Catheter still installed, and me having to clean it and change the dressing daily. He was also still on IV magnesium bags and transfusion dependent when we left Seattle to return to Phoenix. We were very naive about the long term recovery as we had focused on the hospitalization and the ninety days post transplant in Seattle. Because his spleen had gotten so large from the disease and the fibrosis was so extensive in his bone marrow, we were told it would take much longer for his blood levels to come in. He returned to Phoenix transfusion dependent and the doctors really have no idea how long it will take before he can sustain his own hemoglobin levels, or how much more, if any, his spleen will shrink from the chemotherapy.

People have asked me if I kept a journal of my experiences in Seattle. There was simply no time. I did have a group email list to send out email updates. However, as time went on, and the number of people asking to be on my email list grew, I found myself editing my communications more and more to the point where I sent fewer and fewer updates.

We are very fortunate and we know it. I am still the diet and hygiene police, but am no longer an informant for the clinic. My advice to a transplant caregiver: Don't bring your office work with you, try to leave family baggage behind, or put someone else in charge, get some good books, exercise daily, and be sure to pack your sense of humor!

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