

Myelodysplasia  
My Journey – Letters to a Friend  
Shirley M Bulloch

December 2002

Dear Friend,

My journey with Myelodysplasia began on June 1, 2000, when my hematologist, Dr. Yogesh Gandhi, performed a bone marrow biopsy and aspiration. A week later, he told me I had Myelodysplastic Syndrome Refractory Anemia, in simple terms, my bone marrow did not produce enough healthy red blood cells to sustain life. The result would be blood transfusion dependency. I asked him if I should cry, and he told me no. In the past three years, I have cried about six times about my condition. I became determined to fight it and be a survivor. With a positive outlook, I felt that I had won at least fifty percent of the battle. I began with my first transfusion on June 1, 2000, and gradually the time between transfusions changed from 13 weeks apart to 3 weeks apart.

After the diagnosis, I went home and "put my house in order", making plans for the future. Then I put the paperwork aside and concentrated on the future because the doctor would not give me a prognosis. From my reading, I found life expectancy was two to five years. I said to (blank) with that, I had too much to accomplish, and it would be much longer.

During that time, I had the full support of family and friends. My older sister, Charlotte, taught me to make polymer clay jewelry and that was my main hobby. I gave some it away, and I threw some away. On good days, I went shopping. I definitely did not do grocery shopping, I saved my energy for the good shopping - department stores. I continued to cook meals, do my laundry and some small stuff. Ross did all the major housework.

In May 2001, I had a portacath placed in my upper right chest to make blood transfusions easier. During this period, we tried Thalidomide, but I got a reaction and had to stop. We tried the drug Amifostine, but that did not slow the progression. I had Procrit shots to increase cell production, but that did not work. I just knew something would come along.

Dr. Gandhi and his staff and the nurses on second floor east of John Randolph Medical Center became my new family. Without their support, my battle would have been a little more difficult. My family visited often, as it was too tiring for me to travel. During this time, I felt my sisters were becoming much closer to me. They visited twice yearly for sisters' week. We made jewelry and played Scrabble. If I were at the top of the blood cycle, we went out to lunch and did a little shopping at Peeble's Department Store. I felt this whole experience made me a stronger person and I had to keep on believing an answer could be found.

In May of 2002, while surfing the net, I came across the notes from the April 2002, Oncology Conference in Orlando, Florida. It was interesting that much of the conference dealt with the mini-peripheral stem cell transplant. Upon further reading, I found that it might be a possible cure for my condition, Myelodysplasia. I took the information to Dr. Gandhi, and he checked with MCV Hospital in Richmond, Virginia. MCV was one of the centers for the study, a phase II clinical trial. Dr. John McCarty, of the Bone Marrow Transplant Clinic, and his colleagues had the finished protocol for the trial on May 28, 2002. I had my first appointment on June 11, 2002. There were 18 centers in the US taking part in the trial with a total of 100 participants in the original pool with a range of cancers and blood diseases.

The next step was insurance coverage and hoping that I had a sibling match. Finally, we got insurance approval for the whole process. My younger sister and her husband visited in July and her blood was tested. She did not match the first four indicators. There was only a 35% chance that a sibling would be a perfect match. Next, a sample kit was mailed to my older sister, Charlotte, and the first four indicators were a perfect match. It now became an 85 percent chance that the next two indicators would match. The good news came; she was a perfect match.

In September, I started on a chemotherapy drug, 5-Azacitidine, three shots (painful) a day for seven days with three weeks off and then a repeat of the cycle until I had completed four cycles. Wow!!! 84 shots!!! We had a one-week delay in November. When my white cell counts dropped to the neutropenic stage, I got pneumonia and had to spend 5 days in the hospital. I was the first in the nation with MDS to complete the Phase II trial with a pre-treatment of 5-Azacitidine.

Christmas 2002 was great for me although I was neutropenic (low white blood counts). I had my family with me for the holidays. There were nine of us. The grandsons were so cute when holding out their hands for the antiseptic hand cleaner so they could climb up on my lap for hugs and love. It was a wonderful time.

Throughout my illness, my children have come to visit frequently. My husband, Ross, has been here for me with his love and support.

Love,  
Shirley

March 14, 2003

Dear Friend

At the end of January 2003, Charlotte came for two weeks. She had a complete physical, and Neupogen shots to boost her white cell count, which in turn forced more cells into the blood stream. To harvest the cells from the blood, one needle is usually placed in each arm. The blood is removed from one arm, filtered, and returned through the other arm. Her veins were not strong enough for this method and so they placed a catheter just above the collarbone for the process. This process usually takes two to three days. By day four, half of the stem cells needed were collected. The technicians froze the cells, the catheter was removed, and Charlotte went home to Michigan. The process has limits as the platelet count lowers with each day. The body must rebuild. She had been through quite an ordeal, but would not give up until the job was done. She came back at the end of February to repeat the process. By the end of the fourth day, enough cells and a few extras had been collected. My younger sister, Patti, flew up from Florida both times to help and provide the much needed sisterly support. We had several days together without treatment before they left on March 10. I checked into the Medical College of Virginia North Hospital in Richmond, Virginia, on the same date.

March 10th was a good day, after being admitted to the hospital, I gave blood, was hooked to multiple IV's and received the first dose of chemotherapy. The chemotherapy left a terrible taste in the mouth. I cannot begin to describe the number of pills that I had to take each day, must have been between 15 and 20 maybe more. My day nurse, Darlene, had major problems getting the blood samples. It took several hours. One time as she left the room she mumbled, "She just got here, and she is already a problem." I found out later she was a military nurse, and I should have given blood on command. I decided I needed to make her my friend.

On March 11, Ross brought a 20" x 48" table to put the computer on. I also put my get-well cards on the wall and family pictures on the windowsill. He spent a couple hours setting up the table, etc. His next assignment involved making a door sign, "Shirley's Room".

I had another Chemotherapy treatment later in the day. I had to take another antibiotic because of a bug that showed up in one of the white cell cultures. It was either a germ or a contaminated culture.

Food restrictions were in place: no pepper, cheese, spices, orange juice, caffeine or chocolate. Vanilla wafers dipped in applesauce or peanut butter worked for me. Black pepper naturally had its own mold, cheese had enzymes, orange juice was acidic and coffee and chocolate had caffeine. Oh, well!!!!

On March 12, I was so tired that even my feet slept. The chemotherapy and the low blood counts caused the fatigue. I had blood transfusions in the evening as my red blood counts were down to 8.1. MCV provided excellent care. An exercise bike was delivered to my room (Hint! Hint!) I had visitors, and Ross spent part of each day with me.

I received my last round of chemotherapy. Fatigue was the only problem. I was not happy when I heard that I would not develop hair loss. I wanted heavy, curly hair. I growled at the doctor.

I had two units of blood on March 13. My ferritin (iron level) was 1085, down about 500 from the last test. That was great news.

On March 14, I had a very busy day. I received a Pentamidine breathing treatment to protect my lungs. The treatment was followed by 20 minutes of full body radiation. In a pre-admission visit, a radiology resident told me that I could not wear my pajamas during radiation. I was relieved as he was just teasing. When I returned to my room, I received the first stem cell transfusion. The stem cell transfusion was not pleasant. I managed the weakness and light-headedness by focusing on sending Charlotte's stem cells to my bone marrow. I hoped I would eventually receive her artistic talent...must get that sketchpad!!! On the 15th, I received my second transfusion of stem cells. My re-birthday was completed. The physicians' assistant, Rick, transfused me with 24+ little bags of stem cells. Stem cell transfusions smell bad. Everyone knows when stem cells are being infused as the whole hospital wing smells medicinal. I took about 40 pills a day and remained connected to two IV bags. I am sure this is all going to work.

Love,  
Shirley

April 9, 2003

Dear Friend

Well, my re-birthday was completed on March 15, 2003. I was transfused with 5 million peripheral stem cells. They should travel to my bone marrow, live with my cells and take over.

Ross had his work cut out for him. The house had to be sterile for my arrival home. This past fall, we had the duct work professionally cleaned. We bought new carpeting for most of the house in preparation for my return home

I would not change any of my decisions about my treatment. I learned that I was the first at MCV to undergo this type of treatment for my condition and the first in the nation. At some point, I will be the topic of a medical journal case study. I hope that what I have been through will help others. The experience has changed my outlook on life and helped me set my future priorities.

On March 17, I had an episode of gagging and coughing caused by the medications. Ross and I watched "Sweet Home, Alabama" and then I rode the exercise bike for about a mile.

The doctor voiced concern about my low heart rate, and I told him it was normal. A heart doctor checked me and I had an EKG. I have had a slow heart rate since diagnosis in 2000. The heart rate ranged between 40 and 48 bpm. Actually, I felt good, just tired. The waiting began for my counts to drop and Charlotte to take over. I could not wait to become an artist.

The food continues to be bad: breakfast was the best meal. Oh, for baked salmon, butter beans, dinner rolls, and key lime pie!!! Maybe in 6 months!!! I had a piece of pound cake for a snack. It was missing ice cream and chocolate syrup. I have kept a positive attitude. The notebook computer from Scott has made communication easy. Mary came to visit. She brought me a stuffed, dancing, singing chicken and a card. She stayed for about 45 minutes.

As of March 19, there would be no more sugar coating...welcome to the real world of the bone marrow transplant unit! The previous morning I was sick and ill most of the day. I had two more units of blood. Thank goodness for low dosage chemotherapy. I also got the big "D". They gave me morphine at night for leg aches. The doctors remained pleased with my progress. The weakness required me to wait until Nurse Ross arrived to take my shower. Strength must return, so I can continue my independence.

March 20th, wow...still sick! The doctor's diagnosis was that I was normal. The 12-a-day Cyclosporine caused the stomachache. The medication for the stomach made me very tired. I finally figured out what to order from "the menu." The entrees were not for me. I ate soup and sandwiches. I tried to add fruit and vegetables. Canned food does not taste like my cooking. I have lost about a pound a day. Weight loss should stop as my body adjusts to the "drugs."

On March 21, we discovered the stomach problems were definitely from the Cyclosporine (anti-rejection). Phenergan taken before taking the pills solved the problem. All my blood counts were down and I was again neutropenic. I did not have enough white cells to fight off infections. I could not leave the room for the hall walking routine. I rode the bike for a little bit while Ross visited me. The doctors said I was progressing as expected with no unusual problems. I had leg aches at night. I took Ambien to sleep and morphine for the legs. I actually slept for 7 hours. I have not regretted going through the transplant. I had to look at the big picture.

March 23rd marked two weeks in the hospital. My stay would be another two weeks, but if I progressed as I had, I heard that I might go home in a week. Of course, we would not know the engraftment status (my sister's stem cells taking over) for about two months. The first 100 days at home are critical and I must be in a sterile environment, as I will still have a compromised immune system.

I even curled my hair and put on eyebrow pencil and lipstick. I tried to put on make-up and curl the hair daily...could not let anyone see me without the frills! The curl did not last, as I had to use baby shampoo, no setting lotion and no hair spray. I did not think that I had lost even one hair. It would not be thick and curly. The doctor said that I was right where I should be. I was weak, but that was expected.

On March 24th. I had two units of blood. The units were B negative blood. That meant that the majority of my blood cells were B (Charlotte's type) instead of my type AB positive. I was making very few of the old cells. I was a week or so ahead of schedule. The doctors were very pleased. I also received a platelet transfusion. My blood counts should start going up. The platelets are the last to change and go up.

By March 25, Charlotte's stem cells were working at top speed. My own red cells were breaking down in the blood stream, and I turned very yellow. This happened 25 to 30 days sooner than expected. Dr. McCarty would have something amazing to write about in the medical journals. I told the nurse that it was because I was determined and stubborn. She told me that I was stubborn from the inside out.

The headaches and back pain were my only discomfort. They were the result of the chemotherapy. I also had a little nausea after swallowing 15 pills twice daily.

I said a special "thank you" every day for my sister. She gave me a second chance at life. This whole experience has made me a better person ready to enjoy each day that I have been given.

I thought I would be going home on Monday. I was progressing 25 to 30 days ahead of schedule. One e-mail question was about the fact that I would be famous. If I were, nobody will know it, as the medical journal article will probably say a 60-some year old woman.

I was not yellow, just bright orange. The color was caused by the bilirubin. My red cells broke apart in the blood stream, but Charlotte's were fine. When her cells started working harder, I would no longer need transfusions.

On March 28, I knew engraftment was occurring as I had leg cramps and little aches here and there. Knowing what the results would be, I said a thank you for every big and little ache. The plan was to go home on Monday. Beginning on Tuesday, I knew that I would be visiting the bone marrow clinic daily for seven days. I would have blood tests daily. After the first seven days at home, a schedule of visits would be set up. I thought it would be two to three times a week.

I would be glad to have my own bed back. I imagined the pleasure of nestling into my pillows and covers and enjoying my space. The hospital beds gave me a major backache. All the IV changes, blood pressure checks and lights being turned on and off interrupted my "beauty" sleep.

I gave Ross a grocery list. My diet would be limited, but we planned to be creative with the food preparation. Black pepper use at the table is prohibited. Pepper is full of mold. I cannot remember what kind of mold. The only thing that Ross could not find in Ukrop's or Kroger's was apricot nectar. I will drink apple juice, no orange juice allowed for a while. I can add a restricted food item every several days. The first addition will be salmon and then butter beans. I guess you can tell that my taste buds are beginning to work again.

Oh, BTW, I have lost some of my hair. I thought it looked a little thin on top. I could feel new hair growth all over my head. I had hoped for thick and curly.

It was finally March 29, and I would be going home on the following Monday. I walked the halls twice. I slept for two hours afterwards. I used the exercise bike. I know it does not sound like much, but I did ride for 1.5 miles. Considering all, that was good. The bike has a chair seat with the pedals out in front. It also gives heart rate. Mine usually stays between 46 and 56, but I got it up to 102. Then I had to take another nap. I needed to get my strength back so I could walk into the bone marrow clinic on Tuesday. I needed to be as entertaining as before the transplant.

I asked about the little aches and pains, the doctor said it was normal. He also said being tired was fine. He said, "You had a transplant."

On March 30, I waited for my discharge instructions and the visits from the doctor and nurses. My platelets dropped to 31 thousand. If it fell below 30, I would receive a platelet transfusion. Most transplant patients have their platelets drop to 10 thousand. I had been told that the discharge date would be March 31. Well, going home did not happen. I stayed in the hospital because my white counts dropped from 1.0 to .7.

By April 2, I was still in the hospital. My blood pressure went up, and I was given a blood pressure pill. A blood pressure drop followed that to 82/36. After several hours and a blood transfusion to increase the fluids in my body, my blood pressure returned to normal. This was all followed by a fever of 101 degrees. Why? No answers. Blood cultures were taken and I was given antibiotics as a precaution. I guess these things are not unusual for transplant patients. I just chalked it up to another learning experience.

On April 5, I received the news that I would remain in the hospital for about another week. I had a fever ever day. It spiked at about 102 and then returned to normal. It might spike during the day or at night or both. I was given enough antibiotics that anything lurking in my system should have been attacked. I had a CT Scan of the lungs. They wanted to make sure that nothing "funky" was growing there. The report was good.

I told the doctor that I could not hear out of my left ear. I had sinus congestion, so back to radiology and a CT Scan of my sinuses. No report yet. I tried to bribe the aide to take the gurney outside and run me up and down Marshall Street, but he refused.

I was taking about 35 pills a day and antibiotics through IV. I had to receive potassium and magnesium by IV, because my electrolytes were low. I received a growth factor to increase the output of white cells. The medication caused bone pain. Fortunately, IV medications were given at night, and I usually slept through the process.

All of this shall pass. Engraftment of Charlotte's stem cells would be complete within 2 months. Oh, the other day when I showered and washed my hair, I had more hair on my hand. So maybe my hair would be thick and curly.

I continued to hang in there. It was one step at a time, but I knew that I would make it. When I went to radiology, they called me a model patient. I was also one in the transplant wing. All of the nurses were wonderful. My favorite was the one from the first day that had problem drawing my blood.

On April 6, the doctor was pleased when he came in after seeing my blood counts. My hemoglobin went from 9.1 to 9.7 and the hematocrit from 26 to 28.1. Those numbers usually drop and that was why I needed frequent transfusions. Therefore, you see Charlotte's cells were producing healthy red blood cells. My platelets went from 62 to 95. A few more points and I could use a real toothbrush instead of a sponge brush. The most amazing was the white cell count. I received a growth factor to force the white cells out of my bone marrow into the blood stream. My counts rose from .7 to 3.4, which was within the normal range. This all happened in a 24 hour period. Again, I was ahead of schedule.

Now the not so good, but good in the end. I continued to run a fever with it spiking once or twice a day up to 101 or 102. They could not pinpoint the cause, so I was on many different antibiotics daily. Radiology did chest x-rays every Thursday. A pulmonary doctor reviewed the results. Dr. McCarty told me that I might have to have a tube put down my throat, so they could look around in my lungs. Dr. McCarty said I would not feel it or remember it as they would put me in la la land (I spend a lot of time there anyway). I had a sinus CT scan, and it showed a thickening on the left side. An ENT would look around. If they had to scrape, I would be in big time la la land. The good part was that I would go home with only the needed antibiotics.

Now the funny, I had a two-minute pity party. I looked at Ross and said, "Now, Charlotte, no time for a pity party!" I called myself by my sister's name. The other funny, you know how sometime you get tongue-tied. Well, the IV pump started beeping, and I pushed the nurse's call button and said, "The peeping is bumping." I had wanted to call it a beeping pump in the middle of the night.

Even with the little roadblocks, I thought things were going well. My sister's stem cells were taking over, the result being no more transfusions and more energy. I needed to make up for three years of mall shopping. I would set up an exercise routine. I had a different outlook on life.

On April 7, I met with the ENT and Pulmonary Specialists, and the CT scans did NOT indicate the need for any further procedures. Wow! No tube down the throat!!! I celebrated with a great vanilla milkshake instead of a "cardboard" meal.

On April 8, I found out that I might go home the next day. My blood counts improved with the white counts finally in the normal range. I walked 12 rounds of the hall. Ross grocery shopped again and cleaned the house again, even the doorknobs and light switches.

Oh, this is April 9, 2003, and I am about to finish this letter. Yes, yes, I am finally home. I cannot do much as I am very, very weak. Once I get my strength back, I will feel fine. So far, every body part is responding to the wonderful transplant. I do not show any signs of graft vs. host disease. I do not plan to get it.

Ross picked up all my "drugs" this afternoon after we got home. I followed instructions and stayed in my chair while he was gone. We are so fortunate to have insurance as the "drug" bill was \$4100.08 and our out-of-pocket expense was \$56.00. That was a blessing. I think about the people that are struggling through the transplant process without the benefit of insurance.

I am on a limited diet and cannot handle raw or uncooked food. My meals are much better here. I had pineapple, cottage cheese and saltine crackers for lunch. Ross fixed my scrambled eggs, ham, cheese and toast for dinner. I cannot even crack an egg. I had a small vanilla milkshake for my evening snack.

It is good to be home. It is a little more work for Ross. He has all the cleaning and cooking (under my supervision) to do. I help when I can. I will follow all the rules and plan to keep progressing so I can eventually take the survivor's lap in the Relay for Life with my grandson, Matthew.

I start back to the bone marrow clinic tomorrow morning. The time there will vary from a few hours to all day depending on the IV's needed, especially for potassium and magnesium. I will send another letter after I have been back to the clinic and am on a regular visitation schedule.

Love,  
Shirley

April 30, 2003

Dear Friend,

April 10, 2003, was an amazing day. Thirty days had passed since my admission to the hospital. I had my first return visit to the clinic and found out that I had daily schedules. I received potassium and magnesium, had blood tests and medication evaluation. We had been told to plan on staying the day. We arrived at 10:00 and were home before 2:00.

Amazing!!! Tuesday evening blood was drawn before going home, and my hemoglobin was 9.1. On April 10, my blood was drawn and it was 10.1. Usually, my counts went downhill leading to another transfusion. I was finally producing healthy red blood cells that could exit the bone marrow into the blood stream. When I saw the results, I sat and cried - happy tears.

My taste buds returned. I still had hair along with a little new straight fuzz. I started afternoon naps – a trait from Charlotte (my donor). I do not think that I gained her artistic talent, as I have not started drawing and painting beautiful pictures. Oh well, all I really wanted were her stem cells, and they were of the highest quality.

On April 11 at 8:28 AM, I became a new grandmother. Kelli made me the proud grandmother of Cameron (9 pounds 2 ounces and 18 ½ inches long). My sister made it possible for me to be here for the new arrival.

Saturday, April 12th, was not a day of rest. I had to go the clinic. My blood counts continued to rise. After three years on transfusions, I was finally producing healthy red blood cells. My hemoglobin was up to 10.7. That is higher than my counts were when I used to receive two units of blood. There were no signs of graft vs. host disease. My problems were minor with burning eyes and knees that hurt. I was told that I could eat Baked Lays potato chips. I would have some crunch with my lunch. My body needed to learn digestion all over again, so I added one food at a time. Now for the butter beans!

On April 15, 2003, I celebrated the one-month anniversary of my re-birthday. My only complaint was being so very tired. For the first time in three years, I walked out the door, down the driveway, across the street, visited with neighbors, walked back up the driveway and into the house. That was quite an event. When I lived through blood transfusions, I could not do the driveway without difficulty breathing.

I had my clinic visit and received more magnesium by IV. The honeymoon continued with no GVH.

I made a plan to buy new shoes....shopping, shopping, shopping...return to the real world.

On the 14th, I ate rainbow trout, butter beans, and a scoop of ice cream with half of a sliced banana. The only thing missing was the special dark fudge sauce. So far, I have lost 5 pounds.

Kelli and Cameron came home from the hospital on Sunday. Matthew loves being the big brother and has the T-shirt to prove it.

Thursday, April 17th was a long, long day. I had another bone marrow biopsy. La La Land did not arrive until near the end of the procedure. Needless to say, it hurt when the long needle went through the back part of the hip to the center of the bone to draw out the fluid and a piece of the marrow. They usually send me to la la land, but the drugs did not take me there until the procedure was finished. I went to sleep as the doctor was placing the bandage on my hip. I woke up an hour later and was connected to a five hour IV of immunoglobulin to boost the immune part of my blood.

I did have to go to the clinic on Friday for blood tests. We left home at 9:20 and were home by 11:30. Tomorrow I go in again for blood tests and will probably be there a little longer as I will wait for the results in the event that I need magnesium IV.

Unfortunately, I did not have many visitors, as everyone fears bringing in germs. I ordered a few lightweight long sleeved shirts; when outside, my skin must be covered to prevent sunburn. I still needed to get a big hat. Ross put a "baby shade" on the passenger window, so my face would not burn.

I just finished meal number five, ice cream with banana and peanut butter. Good! I followed my usual schedule of starting my pill schedule at 8:00 AM and finishing the daily schedule at 10:14 PM.

The lady will not be famous until about 6 months have passed. Then the case study will be submitted to a medical journal....a 62+ lady....

I also had to go to the clinic on Saturday, April 19, I did cry in the clinic because my hemoglobin was up to 11.1. That was only .3 below the lower end of the normal range. I had not seen a reading like that in at least three years. Charlotte really gave me quality cells. At pre-transplant, my counts would have been around 7.5, and I would have been ready for two units of blood.

My ferritin level went from 1050 to 6000 as my body shed my own red blood cells. The process throws more iron into the system. Another test was performed Wednesday, and the levels had dropped back to 4781. The Desferal pump has continued to be connected to my stomach via a needle every night for 8 hours to inject the drug to lower the iron levels in my system.

I seem to be a little stronger each day with no signs of rejection. How could my body reject the wonderful gift from my older sister! I must never forget the support of my younger sister; she was here both times Charlotte came to donate stem cells. Family is wonderful.

Sunday morning started with the usual pills. I got up at seven and took some pills, then at eight took a few more pills. I finally got up at nine, had breakfast, read the paper, and took two more pills. At 10:00, I went back to bed and slept until 2:15 in the afternoon.

I ate the little chocolate chip cookie. Each nibble was a special treat. Each cookie was about the size of a half-dollar. I made it last for at least 12 bites. I had no digestive problems, so I had another on Monday. Ah, the simple pleasures. The cookies were part of a gift basket from Coram Healthcare the supplier of my Desferal and pump.

I went back to the clinic on April 21. My blood counts were still good. I had an IV of saline because my creatinine levels showed a little toxicity due to some of the drugs. The words were drink water, drink more water.

On April 22, Ross and I made three big pans of lasagna. Along with the lasagna, we took salad, bread, and cookies for the staff in the bone marrow clinic and the bone marrow transplant in-patient nurses both day and night shifts. We made Ross a very small pan of lasagna. It smelled so good. I could not even have a taste.

On April 23, we took the meals to the clinic and nurses. On the way, we stopped to get salad dressing. Ross left the air conditioner on for me. A woman got in her van, got out of her van, peeked around the baby shade, saw a little old "baby", and got back in her van. She probably planned to rescue a baby left alone in a car! I have had a wonderful week. My creatinine levels were still a little high, so I had another bag of saline laced with magnesium. The chocolate chip cookie did not cure all.

The funniest part of my clinic visit was the drawing of blood samples from the double Hickman catheter in my chest. Usually, the nurse just accessed the catheter and drew the blood, but not for me, I did not cooperate. I got into the reclining infusion chair, the chair was tilted back, and it looked like I was going to slide off the chair. Next, I turned on my right side, turned my head to the right as far as possible and threw my left arm over my head. Finally, I did deep breathing. They were lucky and got the blood samples. It was all worth it. For two consecutive days, my hemoglobin was 11.2, that is only .2 from the bottom end of the normal range. My white counts were back to normal.

I have a little GVHD (graft Vs host disease). They say a little is a good thing as my sister's cells battle my remaining cells. Of course, she is stronger and will win!!! This was the only game where I was happy that she was winning. Now, Scrabble was a different story. The GVHD in my system was a little rash and itch on my upper arms. I was prescribed a cream to use to control the itch. It sure helped with sleeping. GVH only affects patients receiving stem cells from a donor.

We got home around 12:30, and after lunch of cottage cheese and pineapple, we went to Peeble's Department Store. I was finally ready for spring and summer, except for shoes. I bought pants, tank tops to wear under lightweight long-sleeved shirts, another long sleeved shirt, and two floppy straw hats. The skin must be covered and protected from the sun because of the chemotherapy and drugs.

I felt so good in the morning. I said a cheerful good morning to Ross and said it was beautiful day and great to be alive.

On April 24, I went to Shoe Forum and bought three pairs of shoes. I had to wear my mask the whole time and I am not even the Lone Ranger....no silver bullets.

On April 25, I went to the clinic, and my blood counts were up again. Charlotte's hard working cells were doing their job. My creatinine levels were high, and I needed more fluids. The Cyclosporine levels must be adjusted to correct the creatinine problem.

On Sunday, we went to Lowe's and bought some bedding plants. I wore my jeans, long-sleeved denim shirt, denim floppy hat and a mask. I do not think I saw anyone that I knew, if so, they would not have known me. I played the pointing game. I pointed at a plant, and Ross picked it up....I could not touch dirt. When we got home, I sat in the sunroom while Ross sat outside potting the plants. I did more; I gave directions!

On Monday, I went to the clinic. I pulled the typical; my body refused to give the nurse any blood. It took two hours to get a sample and then another two hours to get the results. I would be back in the clinic the next day. No treatment was needed, and they sent me home.

April 30th, I went to the hospital and the nurse accessed my portacath to get the blood sample. I had an IV of fluid laced with magnesium. My blood counts were still good. It had been five weeks since the last transfusion. I could not be happier.

They are now lowering the dosage of Cyclosporine (anti-rejection). I have gone from 325mg twice a day to 75mg twice a day. Once I am off the drug, we will know what else might need to be done. Oh, if you have never experiences the smell of Cyclosporine, you are really missing out. It has a very strong smell of castor oil.....ugh....

Since blood could not be drawn from the Hickman Catheter (the one hanging out of the left side of my chest), the doctor said it made blood cultures impossible, and he wanted it removed. It made sense because if cultures could not be done, we would not know if there were any infections. I went to Interventional Radiology at 2:00. They did not provide la la land for this. During the process, they gave me between 8 and 10 injections of lidocaine in my chest. It took quite a while to remove it because my body had accepted it as part of me, and there was a lot of scar tissue. It did hurt. I had just one tear in each eye. I am ready to conquer anything.

I will write again later. Take care of yourself. Life is wonderful.

Love,

Shirley

May 23, 2003

Dear Friend

On May 1, I got up at 7:00 and took some pills. I got back up at 8:00 and took some more pills and then rode the bike for 1.8 miles, took a shower, had breakfast and took some more pills. Then we went to Hopewell and I visited with Dr. Gandhi and my favorite chemotherapy nurse, Janett. Dr. Gandhi took care of me until I checked into MCV hospitals. If you know me well, you know that I have never been a hugger. I do not know whether it has to do with Charlotte's cells or not, but I hugged the doctor. I thanked him for keeping me around until a treatment for my condition became available.

After that, we stopped at Peeble's Department Store again. I really needed another tank top and long-sleeved shirt to go with my khaki pants. I have the hat and shoes to match the pants. Actually, when I get ready to go out and put on the mask, I will not be recognized.

On May 2, I received the bone marrow biopsy results from April 16. As of April 16, 2003, my blood cells were 91% my sister's, Charlotte, cells. The biopsy showed all normal blood cells and no signs of Myelodysplastic Syndrome.

On Tuesday, May 6, 2003, I went back to the clinic for my weekly chest x-ray, a physical, and a bag of fluids laced with magnesium. Everything was fine. On Wednesday, May 7, I went back to the clinic for more IV fluids because of the creatinine levels. The amount of Cyclosporine was reduced. The doctors and nurses consider my condition amazing.

Today I increased the distance on the exercise bike to 3.5 miles. I only ride every other day. I told Ross that I wanted small hand weights for Mother's Day. I am actually in better physical condition than I was three years ago. I seem to get better every day. Sunday afternoon, we walked up and down every aisle in Kroger's Grocery Store. I had not been to the grocery store in two years. I wanted to see if I could find anything additional for meals. All I found was a low sodium, low fat buffet ham.

I made pizza for dinner tonight. Of course, I steamed all the vegetables before putting the pizza together. I put chopped ham on top and then the low-fat mozzarella cheese. It was quite good. Ross had to chop the vegetables, as I cannot touch them. I could not eat much, so there were leftovers.

I feel good and some days, I just put on my hat and mask and we go shopping. I do not touch anything and keep my hands in my pockets. I sometimes wonder if people think I have SARS! One person asked if the pollen was bothering me. I said no. Just let them wonder!!!

May 9th was another trip to the clinic. The blood counts were fine, and I did not need any fluids. The bone marrow biopsies continue, and I have another one on Monday. Around 2:30, I put on my hat and mask and had Ross take me to Ukrop's Grocery. I had not been there in two years. I walked every aisle and tried to find something I could eat to give a little variety in our meals. Not much luck. While he was in the checkout lane, I went out to the car. I got there before the big rain hit. Naturally, Ross got wet.

I guess all the walking today made my legs a little tired. I have more energy. We actually cleaned out my closet. I had five bags of big clothes for the Salvation Army. Time to shop again....

On May 12, my hemoglobin was 11.7. This was the first time it had been in the normal (lower end) range in three years. My white count and platelets were also normal. I was so happy that I had tears in my eyes, and I hugged the nurse. I never used to be a hugger. I also had another bone marrow biopsy. I do not remember much, so I think I made it to la la land.

I hope that after Thursday, I will only have clinic visits once a week. I told them I might have withdrawal as they have become like family during the past 9 months. It sure was worth all the procedures to be where I am today. Not only am I riding 3.5 miles on the bike every other day; I am now using two-pound weights. I may be in better health than I was three years ago. Now if only I could get more sleep.

May 14th, We had a wonderful day; the temperature was about 75 with sunshine and a nice breeze. We went to Williamsburg at 10:00 in the morning and got home around 3:30 in the afternoon. We went into most of the stores at the Prime Outlets. It was a lot of walking, but I did not get tired. We went to the car at 12:30 and I had a peanut butter and jelly sandwich and cold water. We continued shopping. I bought a new outfit at the Koret Outlet, and Ross bought two shirts at the Big Dog Outlet. Naturally, I wore a long-sleeved shirt, mask and hat (Oh, I was fully dressed). We also went to the Westpoint Stevens and bought two sets of sheets.

I did call the doctor's office in the morning to have the trip approved. Then they called me back around 4:30 to let me know that I had to have another IVIG (IV of immunoglobulin). That is the IV to boost the blood immune system. It takes around 5 hours and sometimes has flu like symptoms (fever). I had one a month ago and did not know it was a monthly thing.

May 19th, I had a perfect treat today. I had to be at the clinic at 10:30 and as usual, my creatinine level was high. I had to have another IV of fluids. I was checked by the PA (physician's assistant) and everything else was fine. The treat was—a freshly grilled Chick-Fil-A sandwich. That was my first food prepared outside of our kitchen. It was delicious. The Chick-Fil-A at the hospital has a perfect rating from the state health department and of course, I shared that with Rick, and he said I could have one. I immediately sent Ross down for one, carted my IV stand down the hall to the patient kitchen and enjoyed every bite. Just as important, but not as much fun, my blood counts were all in the normal range today. My Cyclosporine dosage was reduced again. I should be finished with them in about 10 days.

We got the results of my latest ferritin level (iron overload from all the transfusions). In the last four weeks, the level dropped from 4781 to 3500. At this rate, I should be off the nightly Desferal pump in about 2 months.

Next week I should have the results of the bone marrow biopsy. I should be 100% Charlotte. I may have more energy than she does!!! I may have to expend some of the energy and go and buy a few more hats. I really do enjoy dressing sporty for my clinic appointments.

May 23rd, I must tell you about that wonderful grilled Chick-Fil-A sandwich that I ate on Monday. On Tuesday around 5:30 PM, I did not feel great, so I took my blood pressure. Now, I have never had a blood pressure problem. Since the transplant, the medications have slightly elevated the pressure. My blood pressure was 194/106. I immediately called the clinic. They put me on a low dosage blood pressure medication, one per hour until it dropped below 180/100. Within an hour it had dropped. I went to the clinic on Wednesday and my pressure and blood tests were fine. When I got home, I went on the Internet and found that a grilled Chick-Fil-A sandwich has 1000 mg of sodium. Add to that the ham sandwich and dill pickles that I ate for dinner. I was well above the 2500-mg daily allowance of sodium. I have always watched my salt intake due to a long bout with vertigo five or six years ago. I guess I blew it. Monday's pleasure! Tuesday's problem!!

I had my blood pressure cuff checked at the clinic on Thursday. Everything was fine. I just cannot have any more Chick-Fil-A sandwiches. I will have to make my own at home. Now I must check nutrition values on the Internet when I am allowed to eat out (in several months).

My biopsy results showed that I was 92% Charlotte. The blood counts were still good. In fact, my hemoglobin was in the normal range. I have not had a transfusion since April 8, 2003. I was getting them every three weeks. I have to learn to channel my new energy and still follow the rules - no housework (no problem), no lifting over 5 pounds (I use 2 pound weights), no going out of the house without a mask (hot inside, but no need for lipstick), no eating out (Ross and I prepare meals together, I direct). I cannot shop during peak shopping hours. I have been to the grocery store, but the mall is better. The other day we walked the mall, but I did not buy anything. I either walk or ride my bike every day. Ross does the housework; I think I will keep it that way.

I will write again soon.

Love,  
Shirley

June 30, 2003

Dear Friend

May 28, 2003...After another clinic visit, I learned that all my blood results were good. Another five days and the Cyclosporine would be finished. My only complaint was fatigue.

June 02, 2003...Another clinic visit and more good news. Blood tests were good, and the Cyclosporine was finished. Clinic visits will only be weekly, and shopping with the masked woman will be daily!

June 10, 2003...I developed a rash from neck to toes and thought, "Here comes the GVH" (graft vs. host disease). The clinic sent me to the dermatology department Monday afternoon. The doctor said it did not look

like the classic case of GVH. It was probably an allergic reaction to something. They did a skin biopsy on my back. I was told it would be painful after the lidocaine wore off. No pain, no discomfort. It was the size of a pencil eraser and had two stitches. The doctor in the bone marrow clinic put me on the six-day supply of Prednisone as a proactive measure until the biopsy results were received.

I am still riding my exercise bike, four miles every other day. I have been shopping on the sunny days and just enjoying myself. I have added a few things to my diet. I can now legally eat a square of special dark chocolate as an evening snack. I tried my favorite orange juice with calcium. I did not like it. Ross had to finish it. I lost more weight and returned to a size 12.

June 16, 2003.... Saturday evening, I called the clinic as the palms of my hands were quite red and the skin felt burned. The nurse contacted the doctor and he wanted me in the clinic on Sunday morning. Dr. McCarty said I had stage one (mildest form) skin GVH (graft vs. host disease). A little GVH is a good thing. It again proved that I had a new blood system. I was told that if it got worse, I would have to be on steroids for a while. It looked much better the following morning. I used a steroid cream on my hands. I told a friend that my only problem was that I could not work on my polymer clay jewelry for a while.

I went to the clinic for my monthly immunoglobulin IV, a three-hour process. I also had blood work done. I was quite pleased with the results. My hemoglobin was 13.5. I had lost 3 1/2 more pounds since last Thursday. I found out that I not only had my sister's blood cells and DNA, but my whole metabolism had changed. It was also possible that I had some of her allergies. All this was good news. Her blood cells were working hard...no blood transfusions since April 7, 2003. Before the transplant, I received two units of blood every three weeks. That was all behind me.

I went back to the clinic on Thursday so the doctor could check my hands. I was scheduled for another biopsy on June 30.

June 24, 2003....Last Tuesday, Kelli, Mike and the boys arrived for the long awaited visit. They stayed until Friday morning. Originally, they had planned to leave on Thursday, but the car air conditioner problems delayed their departure for 24 hours. Of course, I did not mind at all. I enjoyed the grandsons. Matthew still had hugs for grandma, but not as many as usual. Cameron, age 10 weeks, was pure pleasure. It was my first visit with the new baby. I felt a little let down when they left for DC, but they stopped back for about an hour on Sunday on their way back to Georgia.

Well, I was still doing fine with only a few bumps in the road. My blood counts were high and all my blood chemistry was great. A little GVH started in my mouth with no visible signs; just a burning. I am now using a special swish, swirl and swallow mouthwash. It was supposed to be very bitter, but with impaired taste buds, it tasted fine to me. My taste buds left a week ago. Only special dark chocolate had any taste. The skin rash was better, so I did not need to go on Prednisone. That was good; I did not want the weight gain or the "fat" face!!!

My platelets started to drop below normal, so the doctor stopped the Bactrim. As of Monday, the platelets started back up. I would not go back on Bactrim (for the lungs). I asked if the new drug would cause side effects and the answer was possible liver problems. Since the breathing medication once a month does not have harmful side effects, I asked to be put back on it. It takes about 20 minutes once a month. The doctor said that it might cause an upset stomach. I told him I could deal with that.

I continued to read about everything (drugs, etc.) on the Internet. The doctors gave me information and then I gave them my "medical" opinion!!!

I asked if I could have a hotdog. The answer was a definite no as was the addition of Cheddar cheese and salad. They would not let me add anything new to my diet. It was possible that I would eventually be able to go out for a meal. Good luck....no seafood, no fried foods, etc. I am happy with my Morning Star Prime Griller with three pickle slices, mayo, and whole wheat bread (when I can taste). Hmmmm, one friend wanted to take me to lunch. I decided to invite her to our home. I wondered if she would like a Morning Star Griller!!!! (a glorified soy burger) For dessert we could have my favorite....banana, low fat vanilla ice cream with a glob of peanut butter on top. I could bake her some chocolate chip cookies!!!

June 30, 2003.... I had my bone marrow biopsy in the morning. I was fine, but tired from the drugs. I did talk while in la la land. I told the nurse about the people on the elevator with fat stomachs and fat necks and that they needed to do something about it.

I got a call from my nurse, Judy, with my blood results. I was very pleased except for the platelets that dropped from 112 to 85. I was told not to worry as Dr. McCarty thought that it was caused by the GVH. Platelet transfusions would only be needed with a drop below 20. We did not think that would happen.

I started taking 60 mg of Prednisone a day, and experienced relief from the burning hands. I hope that by Thursday we would be able to cut the dosage. With the GVH getting better, my platelets should be going up. I was very pleased with my progress, as were my nurse and the doctor. The nurse told me that I looked great. I actually slept for six hours the night before and would have slept longer except I had to be at the clinic early.

Must close for now. Thank you for being such a good friend.

Love,  
Shirley

September 1, 2003

Dear Friend

July 3, 2003...The GVH on my hands continued to improve. My blood counts were great, my platelets rose from 85 to 115 in four days. Everything looked good. Now I had to get rid of the GVH. I cried when I got the results because my hemoglobin was up to 13.3 from 12.9 and my hematocrit was up to 37.2 from 36.3. I am well into the normal ranges.

Remember the friend that I offered lunch of a Morning Star Griller (soy burger)? She said she would settle for a peanut butter and jelly sandwich. I guess I will wait until I have my taste buds back and then fix a real brunch. I do enjoy cooking. I can make some good breads, etc. With my problem hands, I have not been able to make any jewelry lately, but I can cook.

July 15, 2003...On July 14, we spent our 41st anniversary at the clinic. I had blood tests, a 4-hour immunoglobulin IV and a physical. My blood counts were great and my liver enzyme levels were headed back to normal. The Prednisone continued for the skin GVH. My legs were all clear, but I had the rash on my upper body. I love Prednisone!!!!!! I was beginning to look a little like a chipmunk. It would go away once I stopped the Prednisone. Thank goodness. I must wear a mask when I go out. That way, my chipmunk cheeks stayed hidden. The doctors said I was extremely healthy and little GVH was good. It showed that my blood was strong and my Myelodysplasia was completely gone.

We went shopping, and I took advantage of some big sales. I bought four more long-sleeved shirts and a pair of slacks. We went to Pier 1 Imports and I bought two covered baskets for storing my pill bottles. Kelli suggested it since I had to have the stuff sitting out; baskets would be better than cardboard boxes. I agreed; it did look better. She also suggested that we rearrange the contents of the shelves in the living room. Originally, I had books on one shelf, pictures on another, etc. We arranged them in an HGTV show type arrangement. Since I had to wait for my hands to heal, I could not work with the clay jewelry for a little while longer. These little projects kept us busy. I kept Ross busy with grocery shopping and his "honey do" list. I did most of the cooking, my laundry and the little stuff. I rode my "going nowhere" bike at least two miles a day five days a week.

July 27, 2003...Another bone marrow biopsy is scheduled for July 28. I have them put me totally into la la land. The last time I talked about people on the elevator. I said that they had thick stomachs and necks, I was worried about them, and they should do something about it. I hope I keep my mouth shut this time.

My Prednisone dosage dropped to 20mg per day. I still looked like a little chipmunk, but had not gained any weight. I lost more. The Prednisone not only caused large muscle weakness, but bone pain in the hips and knees. By afternoon each day, I had the pain under control. At least my GVH (skin rash) seemed to be improving, but my taste buds were still gone. I tolerated it considering the health of my blood. The Myelodysplasia was gone, not in remission, but gone.

One friend said she told someone that I had good days and bad days. In truth, I have had good days and a bad few hours here and there. One of my other friends dropped in for 2 minutes to bring fresh sweet corn and butterbeans. Oh, she gave Ross two tomatoes.

We have been busy. I mean Ross has been busy. I just supervise. We plan little projects. We have a small bedroom upstairs that Ross has been using for his computer room. I decided it needed some changes. He built book shelves above the computer table, and we went to Pier 1 Imports and bought a loveseat sleeper, pillows and new curtains. Now when the kids visit the grandsons can have their own room.

I have also been doing some recipe research on the Internet for foods that I can eat. I am going to put them on 4 x 6 cards. I was told that I could not have Alfredo sauce because of the high fat content, so I found a fat-free recipe. I have quite a collection of fat-free or low fat recipes to enter into the computer. I am going to call it, "When Taste Buds Return!"

I started making clay jewelry again. I made some neat face pins and pendants.

September 6, 2003...My blood counts were still great, and the Prednisone ended. Because of the Prednisone, I was still having problems with bone and muscle pain in my legs. The cane came in handy until I got moving. The next step was to do a different procedure than medications to get rid of the GVH (graft vs. host disease). I had a liver biopsy at the beginning of August and had a double catheter placed in my chest below the collarbone. The liver biopsy was transjugular. Nasty details, but fortunately, I did not have GVH of the liver. The catheter was placed in the right side of my chest because I am now receiving Photopheresis twice a week for two days each week for the next 8 weeks, then once monthly. It does not hurt, just sitting for about 21/2 hours. The blood is removed in six cycles, the white cells are separated from the rest, and the remaining blood is returned at the end of each cycle. The white cells are treated with a drug and photosensitive light to alter the DNA of the white cells. After treatment, the cells are returned to my bloodstream. My sister's white cells are fighting with my remaining few and this causes GVH. I should see the results in several months and may be on this procedure for a year or two.

I will write again soon. Take care!

Love,

Shirley

November 1, 2003

Dear Friend,

Since my last letter, Kim and Tyler have been to visit. When Kim was here, we took Tyler (age 5) to the Farmers' Market and he selected his own fruits and vegetables. He loves all vegetables, but we talked him out of okra, as Kim has never prepared them. We took a picture of him sitting in the back of a truck holding the watermelon he had selected. He took two coolers of fresh produce home with him. He also took some of the other vegetables that I had in the fridge.

October 1, 2003. I was admitted to the hospital on September 22. I may go home next week!! I had extreme difficulty in breathing and was diagnosed with GVH of the lungs. I had an Echocardiogram, a Pulmonary function test, a Stress test (Chemically Induced), an Electrocardiogram, a CT scan of the lung, a Bronchoscopy, an ultrasound of the liver and lower right lung, and a vascular ultra sound of the right arm which had become swollen. They checked for a blood clot in the arm. The test was negative.

All of the above listed tests were negative and ruled out other causes for her breathing problems. My comment was "Finally a diagnosis!!!!!!". The diagnosis was GVH (graft vs. host disease of the lungs). A new nurse was in training in the transplant wing. Well, Margie and I hit it off. We laughed all the way through the lung GVH. Really, laughter is the very best medicine.

The doctors put me back on the nasty Prednisone. I did not like being on this drug, because of the past experience with hip and joint pain. I told Ross that I might have to relent and use a walker.

October 31, 2003... I checked back into the Bone Marrow Transplant unit at the Medical College of Virginia on Monday, October 27. My blood sugar had shot up to 600. I probably should have been in a coma. Not me!!! I had extreme mobility problems. I could not climb steps, had difficulty walking and could not get out of a chair unless Ross pulled me up. The problems were caused by the Prednisone. I was extremely weak and required assistance in performing basic tasks.

While in the hospital, I received physical therapy to strengthen the muscle groups that would allow me to sit up and do less labored leg movements until the initial drug that has caused some of these problems can be reduced sufficiently or eliminated. I am working with large rubber bands to strengthen legs and arms so that they become stronger and more usable. This was the only time that I was extremely depressed and wanted to quit. After two days, I realized I had too much to live for and decided to continue the fight. It did not hurt that Dr. McCarty gave me a big lecture.

They are trying to reduce or eliminate some of the many different drugs I am taking. Because of the blood sugar problem, I was placed on insulin to bring the level into the 100-150 range. Once the Prednisone was eliminated, the blood sugar would return to normal.

I will write again soon,

Love,

Shirley

December 22, 2003

Dear Friend,

December 4, 2003...The Prednisone continued as did the insulin with a shot each morning administered by Nurse Ross. The Prednisone also affected my legs again. This time it wiped out all the muscle use of my legs from the knees to the hips. I could not get out of a chair without Ross pulling me. I had to resort to sitting in the computer chair (as high as it would go) with a pillow or two on it. Walking became almost impossible. I had a couple of down days in the hospital (big time pity party) and felt like a burden. I came home to a hospital bed and a walker and was supposed to have a physical therapist. I was at home for two weeks before I had a therapist. I did many the exercises on my own. I came home on November 6.

I set a goal to make it to the main level (kitchen, dining, living room level) by Thanksgiving. On arriving home, I could lift my left leg about 2 inches. On Thanksgiving Day, I made it up the four steps to the dining area for dinner. Of course, I used the railing to help drag me up the stairs. I saw the therapist once a week and progressed to walking around the back yard without the walker.

When I went back to the clinic, I had to show off for the nurses and doctors by walking the long hall without the walker. The following week I managed to get to the bedroom level of the house. I mastered the 10 steps up and down. I got up by pulling on the railing with both hands. The following week, I mastered walking up and down the driveway hill. By Christmas, I planned to be finished with the hospital bed and be back upstairs at night. The Prednisone takes away, and stubbornness and therapy return the muscle use.

The lung GVH had not returned and my skin GVH has gone. I had another bone marrow biopsy while in the hospital, and the transplant has held, I am cured of the Myelodysplasia. I am still my sister!!! I have her DNA and blood type. I now must take allergy medicine. I even lost my loud Mason sneeze and have a dainty little one. Oh, I am now a size 10-12. In fact, the nurse called me today and said that because of Monday's blood chemistry results; I did not need to keep my next appointment. I hope that my visits return to once a week.

As I look back on this year, I have decided that if I had to make a transplant choice again, I would do it all over. A transplant patient never knows if GVH (graft vs. host) will show its ugly face or not. I still have too much fight to give up.

December 22, 2003...This a busy time for you, and I hope your holidays are happy ones. This will be my last letter of 2003. Part of my family will be here for Christmas. Kim and her son, Tyler, are coming from North Carolina, and Scott is flying in from California. Kelli and her family will have their Christmas at home in Georgia.

Today was bone marrow clinic day. All of the news was good. I took my last Prednisone today. I have been on insulin since shortly after starting the Prednisone. The doctors said that the blood sugar problem was caused by Prednisone, and the sugar problem would go away. Today when we checked the sugar levels, they were normal and I did not need the insulin. My blood counts were normal. I had been getting a three-hour IV of immunoglobulin every four weeks, but no more for at least three months.

I may have mentioned at one point that I had to receive a drug through a pump for eight hours a night for iron overload caused by 2 1/2 years of blood transfusions. My doctor took me off the drug about two months ago, but I still have the iron overload. The other way to remove the iron is by drawing blood and throwing it away. Now that I am a different person and producing blood, they can draw blood. One unit will be drawn and thrown away every other week to eliminate the iron. I have no signs of GVH (graft vs. host disease). It is also official, the last bone marrow biopsy shows that I am now 100% my sister.

My physical therapy is going well. After Christmas, I will move back to the upstairs bedroom. Using the railing to pull on, I can now go up the ten stairs. I can get in and out of the bed. The hospital bed will be returned after the holidays. I will go upstairs at night and come down in the morning. I can now walk most of the time without using the cane. Oh, I can also stand up from any chair in the house. I do not even have to put a pillow in the seat.

The doctor was pleased when he saw me walking the halls today. He held out his hand. I hesitated and then told him that I did not do hands or doorknobs. I asked when he last washed his hands, and then I shook hands with him.

Have a wonderful holiday season. Give my love to your family.

Love,  
Shirley

March 2, 2004

Dear Friend,

January 8, 2004....I was no longer receiving physical therapy. I made one trip upstairs each day. I relied on the railings to make the trip. At the top of the stairs, the railing ended even with the top step. Ross added a

small railing so I could drag up the last step. I had stopped taking insulin before Christmas. The high blood sugars left as quickly as they arrived.

Remember when I had the high iron levels because of the numerous blood transfusions. I had my first phlebotomy. I am now a producer of blood, so they have started to reduce the iron levels in the blood by removing a unit of blood every other week. The blood cannot be a donation because of the drugs (medicine) in my system, but it can be used in research.

The other day, I had a piece of fried chicken, the first since February of 2003.

Houseplants are not allowed for transplant patients. A friend has had my plants since January of 2003. I asked the nurse when I could have them back. The only answer was "not anytime soon". There was one special plant that I really wanted to have in my home. It was an unusual peace lily with green blooms. It was given to me when my father passed in 1989. I did not know that it was a peace lily, as it did not bloom until the day I was diagnosed with Myelodysplasia in 2000. In my mind, that bloom had a special meaning.

I talked with my Nurse Judy. If I continue to progress, I will meet a goal that I set on transplant day (March 15, 2003). I will be able to go to Marietta, Georgia, in May to walk the survivor's lap with my grandson in the Relay for Life. Whenever I think about the opportunity to walk with him, I get a tear in each eye. I must continue to work on endurance in walking.

I knew that I was getting better because I started working with clay again. I had not made any jewelry since my sisters were here last February (2003). I made some pins and a couple of necklaces. It felt good to be working with the clay again, but it did cause a "little" clutter in the kitchen.

February 7, 2004....I no longer check my blood sugar levels. They had been normal since mid-December. A square of special dark chocolate after dinner provided a special treat.

The blood treatment (Photopheresis) continued to change the white cells so I should not have any more graft vs. host disease (GVH) or should not have the need for any future Prednisone. At one point, I had the record time of 2 hours and 22 minutes. Then a young man broke the record and an eighteen-year-old girl broke his record at 2 hours and 11 minutes. Well, I fooled them; the old lady finished the process in 2 hours and 8 minutes. My sister asked if there was a prize — just bragging rights.

I finish the immuno-suppressants in about three weeks. I have really enjoyed my clinic visits; the doctors and nurses are a second family. The visits are my weekly social event.

Fried Chicken became a Friday ritual. Ukrop's fried chicken and potato wedges!!! HMMMM!!!

On February 28, we went to the Bone Marrow Transplant Reunion in Richmond. The attire for the evening was either casual or tropical; I went casual. There must have been about 175 people there with at least 70 stem cell transplant survivors. The rest were guests, doctors, nurses, and other staff members. When we first arrived, we had our pictures taken. They were projected on a screen during the evening as a slide show, (so Prednisone, chubby cheeks had her face on the screen more than a few times.) They served heavy appetizers, provided musical entertainment and three doctors and three patients spoke. The evening concluded with chatting among the patients, guests, and medical staff. The reunion started at 6:30 and ended at 9:00. That was past my bedtime.

I have had four units of blood removed and my ferritin (iron) levels have dropped from 1450 to 450. A few more units and my count should be below the normal level of 50. I was getting Procrit shots to boost my hemoglobin levels, but the shots have been stopped since my hemoglobin was 16.5, above normal.

Kelli, Kim and the three grandsons were here the weekend of February 14. It was a wonderful weekend. We enjoyed the grandsons. Ross took Matthew and Tyler shopping on Saturday afternoon while Kelli, Kim and I played with Cameron. Saturday evening we sat around the kitchen table after the boys were in bed and we laughed until 11:00. It was by far one of the best weekends in a long time. It was wonderful having them here. I really enjoyed myself because my energy level was high.

March 1st was another clinic day. I thought that it would just involve my monthly chest X-ray and blood work. Wrong!!! I was informed that it was bone marrow biopsy time again. My last one was at the beginning of November during my last hospital stay. I hope that the drugs will put me into a deep la la land

I planned to take them my birthday cake (not yet baked) as a thank you for getting me to birthday number 64 on March 2. I have two birthdays in March. March 15 is my first re-birthday. I told Ross that I expected two gifts. I still get tears in both eyes when I think of that March 15 event. The tears are sentimental for everything my sisters did for me (Charlotte and her stem cells and Patti and her support), my family support, and the expertise of the doctors and their staff. The doctors and nurses are like an extended family. I actually look forward to the clinic visits.

Last week was busy. I had my clinic visit on Monday. I went shopping (the masked woman) on Tuesday (Peeble's sale, new glasses and stuff from the drug store to make my face "look younger"). On Wednesday, we went to the mall because Dillard's was having a sale. My sisters know how I do not like to miss a sale; I bought three shirts, as I must wear long sleeves whenever I am outside. Thursday and Friday were for rest, and I made a necklace to wear Saturday to the reunion.

I am still looking forward to our trip to Georgia the first weekend in May. I will be in the relay for life with Matthew on that Friday evening. On Saturday, we will go to church with Kelli, Mike and the boys, as Matthew will have his first communion. On Sunday morning, we will drive to North Carolina and spend the afternoon with Kim and Tyler. We will head home on that Monday morning. I have not been out of the area since 2001, so this is quite an event for me.

Must get a few things done. I miss not seeing you.

Love,

Shirley

April 19, 2004

Dear Friend,

April 15, 2004....I hit another bump in the road. The bump landed me at MCV hospital in a hospital bed. Maybe it was not a bump in the road, but it was definitely a pothole. The doctors finally put me back in for heavy breathing (actually extreme difficulty after any physical movement). After numerous tests, it was determined that my blood albumen was too low, causing the body tissues to retain too much fluid. I had swelling in my legs all the way to the sacs around the lungs. The fluid pressed against the right lung causing it to be shaped like a pancake (seen on a CT scan). The pressure would not allow the lung to inflate. With IVs of Albumen and Lasiks, the problem should be corrected. The above was a result of care by the lung team (three doctors). Congestive heart failure was not fun.

NOTE: A good picture would have been of the three doctors. The first looked at the infection in my mouth with a flashlight and the other two were lined up behind the first. They each leaned over a little so they could all see in my mouth. From my point of view, it was very comical.

Now the bone marrow team – I was placed back on my favorite, Prednisone. I was also placed on anti this and anti that. A new drug was started to shorten the time on Prednisone. After 13 pills, a lung puff and a mouth rinse, I was ready for the Ambien and morphine.

I know this may all sound daunting, but it really was not. I asked the doctor my favorite question: "Will I make it?" He said I was not going anywhere. I was told to plan on my trip to Georgia.

I was admitted on Friday, and thought I would only be in the hospital through the weekend. When I went for my clinic visit, I had my bag packed and in the car. I was prepared to be admitted. Ross came daily with frozen entrees for my dinners, as the hospital food was not among my favorites. Ross spent each day with me, and I greatly appreciate his love and care.

The lower dosage Prednisone elevated my blood sugar levels, so I was put back on insulin and physical therapy to strengthen my muscles before the Prednisone tried to do its job.

I did some intense thinking while confined to the hospital bed, and I am really blessed. I have a loving husband, children, and grandchildren. I have loving sisters, their spouses and children. I have Kelli's husband, Mike and Scott's girlfriend, Renee. I can add the friends that still stop by and call as my extended family and are very dear to me. I am blessed with each month (13 now) since the transplant. That is an additional month at a time to enjoy my family, my friends, my hobbies and shopping! I am blessed to have had two caring giving sisters; they have become a bigger part of my life. Ross and I have become quite a team. I may start something like dinner preparation and become too tired and he is right there to help or finish. I get what I need with no complaints and no questions asked. He is a true blessing. I am blessed to be able to bounce back and see the real me. I am blessed because I can now look to a higher being and say thank you. I am blessed as each month means more time to get things done. The most important is seeing those three grandsons grow.

I will go home soon.

Love,

Shirley

April 29, 2004

Dear Friend

April 20, 2004....Well, I did not go home from the hospital as I woke up to chills and a fever of 101.7. I was diagnosed with pneumonia in the good old right lung. I guess I hit another pothole on the road to recovery. The doctor said I should be better in a few days. I had pain in the right side; I was prepared to deal with it, but they gave me a little morphine.

April 28, 2004, I came home from the hospital Monday afternoon with oxygen. I am getting stronger at home. I still have to go to the clinic twice this week. I do have an antibiotic IV three times a day at home to get rid of the Psuedomonas that I got in the hospital. I am going to be fine when the strength is back and Prednisone is gone. I never really knew how very sick I was while in the hospital. I was just so determined that I could fight anything. I guess some thought that this required too much fight. I was up to it; I have too many things that I still want to do.

The first thing I must do is nap. More later.

Love,

Shirley

July 17, 2004

Dear Friend

May 3, 2004, I guess you have figured out by now that I did not walk with Matthew in the survivor's lap in the Relay for Life in Cobb County, Georgia. Kelli walked in honor of three people. She walked for Matthew, for me, and for Mike's aunt. I met her at Kelli's wedding and in my own way she has been in my prayers. I am proud of Kelli; she even had some Cub and Boy Scouts walking with her. I may have been in Virginia, but my heart was with her in Georgia.

I progressed, except I dropped more weight. I have rosy cheeks and look healthy, but I only weigh 124 pounds. I never thought I would say that I needed to gain about 5 pounds.

May 24, 2004....I would have written sooner but they put me back on all these medications, and I have been fighting Prednisone and some other nasty drugs that mess with me - shaking, dizziness, blood sugar, sleepiness, weakness, etc. It made using the keyboard difficult.

My attitude has been fine, and I have maintained my sense of humor. I guess I did not say that while I was in the hospital, I was in ICU for 16 of the 17 days. It does not seem possible that I have been home for 4 weeks. When I got home, we had to continue with the antibiotic IV's for an infection in one of my Hickman catheter lines. Well, one morning Ross hooked me up to the IV and I did the usual. I rolled over on my side and went to sleep. About ten minutes later, I woke up and felt very strange!!!! I was lying in a pool of blood; I had somehow popped the tubing and was bleeding in the bed. We turned off the lines and cleaned everything up. I called the clinic and was told I had done everything the right way. The next day at the clinic, they did a blood check and calculated that I had lost one and one-half pints of blood. I did not have a hospital phlebotomy to remove the excess iron. I had already done my share at home in an unconventional way. Fun! Fun! The only thing that angered me was that we had to buy a new down mattress cover.

I have an IV every evening because of low magnesium. It only takes about an hour. I stay on my back and remain observant. We are gradually lowering the Prednisone dosage, but it has already affected my legs with some weakness and one of the drugs gives me blurry vision. As soon as the Prednisone is gone, my blood sugar will return to normal, and I will be off the insulin.

My weight did drop to 121 pounds, but I am now at 128. They dried me out too much, and I had to go to the clinic three days in a row for fluids. I think I am now where I am supposed to be. I would like to get to 135. I never thought I would want to gain weight. The purple-red spots/bruising on my arms are from the Prednisone. That drug has also caused some hair loss.

Ross put some impatiens in the eight pots around the patio and Mary brought me two nice tomato plants to put in the large pots next to the house. I have about eight blossoms on the tomato plants. She also brought freshly picked strawberries. My taste buds are almost non-existent. I can taste some fruits and chocolate. I am eating for the protein, not for the taste. The doctor thinks that my taste buds will return after some of the drugs are stopped or within a year!!!!!! I have enjoyed the Healthy Choice 2-gram sugar chocolate ice cream bars. I have at least two a day.

A couple of weeks ago, Kim and Tyler (age 6) came for Mother's Day weekend. Tyler was fascinated with my medical care. He had to watch the shots, etc. He watched while his "Poppy B" gave the shots. Tyler and his "Poppy" went shopping and out to lunch. I really enjoyed their visit.

Well, I have gotten stronger each day as the drug dosage is reduced. I will soon be back to shopping. Right now, I must enjoy being lazy. I called the department store and got permission for Ross to use my discount coupons and credit card. I certainly could not miss the sales.

July 16, 2004....I finally finished the Prednisone, and my blood sugar returned to normal. The Prednisone problems continue with the reduced muscle strength making the stairs difficult. I have had to return to the downstairs bedroom. I had another round of fluid in the lungs, but we caught it early. When I went for my weekly checkup on Wednesday, the doctor said my lungs sounded clear. The shortness of breath has improved, so I do not need to use oxygen as often.

My hands still shake at various times throughout the day from one of the drugs. The drug dosage has been gradually reduced, so many of these little problems will go away. I have not been able to work with clay as my hands might start shaking and I would be flinging the clay beads all over the kitchen. I have experienced a little boredom.

We were very pleased with my last series of blood tests checking the iron levels from all those years of transfusions. Finally, the ferritin levels (iron) are down, and I no longer need shots to build the blood followed by the phlebotomy. I have not had a phlebotomy since I did the big one at home in May.

Food looks good, but I still cannot taste much of it. I enjoy fresh corn, peanut butter, applesauce, and chocolate. I cannot taste much of anything else. Ross helps with the meal preparation. My meals are simple....juice and cereal for breakfast....an ear of corn, cottage cheese and homemade applesauce for dinner. I have been drinking four Ensures each day. The best is the 10:00 PM snack....peanut butter and a square of Hershey's special dark chocolate. No problems eating the chocolate as I only weigh 120 pounds.

Now that I am off the Prednisone and my lungs are clear, I need to start exercising more frequently. I have exercised my computer fingers enough, and must close now. Take care of yourself, and I look forward to a visit from you.

Love,  
Shirley

November 1, 2004

Dear Friend,

I noticed that I had not written to you since July. The last half of July and August were busy months.

Regarding my health, all my blood tests have been fine. I still have some reactions to the medications. I am light-headed in the evenings; I was using the term "empty-headed", but too many people were agreeing with me!!!! I still do not have many taste buds, but am trying to eat. I can taste sweet corn, low acid orange juice, ice cream, peanut butter and applesauce. Tuesday I did eat most of an Arby's stuffed baked potato; it tasted better than the ones fixed at home. I now have to keep track of everything I eat because I only weigh 107 pounds. The doctors seem to think the weight loss may be related to the medications.

My hands no longer shake, as I will be finished with the immuno-suppressant (gradual reduction) in 10 days. I no longer need the magnesium by IV at home, as my levels returned to normal. As soon as I finish the immuno-suppressant, we will start reducing another medication. In about six months, I will be able to start my "baby shots".

I am now 17 1/2 months out of transplant and according to the doctors; I am doing quite well. The doctors and nurses told me that I looked good, just a little thin. I am so happy that I was able to have the transplant. I plan to be around for another 10 years.

I did enjoy visits from my daughters, grandsons, and son-in-law Mike. Kelli, Mike, Matthew and Cameron came for a visit from July 24 to July 26. I really enjoyed their visit and wish I could travel to see them.

Kim and Tyler came on July 30, and Kim went back home on August 1. Tyler (6) stayed here until August 4 when his "Poppy B" took him halfway to meet Kim. Ross took Tyler to play Putt-Putt Golf, and Tyler loved the water blaster boats. He especially liked spraying his "Poppy B" with water. We tried to plan something for the two of them to do each afternoon. While they were gone, I napped.

On August 8, we had the "big event". I had decided to go shopping, so I got up at 8:00 to shower before breakfast. I usually shower after breakfast. I had showered and was standing in front of the sink. I started to feel light-headed (not unusual), then it became more intense. I thought it seemed strange to feel so bad. The next thing I remembered was hitting my head on the doorframe. I have no idea how I ended up on my back on the floor. Now I know what it feels like to pass out. I called Ross, but naturally, he could not get in to help me because I was blocking the door. At that point, I thought the whole thing was funny and started laughing. I still had the problem with my knees, so I remembered how the therapist taught me to get up from the floor if I ever

fell. It worked. I crawled to the commode, put my arms across the seat and managed to pull myself up with my arms. I was quite angry because I decided that I better not go shopping. I told the nurse and doctor about "The Big Event" when I went on the ninth. The results were bruised knees, a few bruises on my back and a sore spot on the side of my head. I guess the cause was lack of food or becoming overheated in the shower. I did manage to go shopping of the 10th.

On the 17th, I had my immunoglobulin IV and again I had a reaction to the IV. The nurse gave me Demerol through IV to stop the reaction. At that point, I saw six nurses instead of the actual three. I will no longer get immunoglobulin. The doctor hopes to find an alternative. I have planned to be stubborn and keep my levels high enough so I will not have to be given the IV. I was supposed to go back on the 31st but had to wait until September 1 because of the road flooding after the hurricane. When I went on Wednesday, I learned it was time for another bone marrow biopsy. I must have them every three months. It does not hurt as they give me loopy drugs before they begin. The only problem is my mouth; I talk continuously and tell them all sorts of things. I cannot put in writing what comes from my mouth. My goal is to mumble.

I started making clay jewelry again as my hands do not shake, and messy the kitchen table has returned with clay, tools, and other equipment. I have done more towards meal preparation (wearing latex gloves) and doing little things around the house. I have been very happy that I am not allowed to dust, vacuum, or do general cleaning. Ross does all the major cleaning. I plan to keep it that way forever.....

September 25, 2004....I have had a few more accomplishments. I no longer weigh 107 pounds; I am up to 108.

I received the results of my last bone marrow biopsy and everything is fine. The report still shows that the transplant was a success. It has now been over 18 months. I did talk continuously during the biopsy because of the drugs. I had no idea of what I said until the nurse told me. I turned my head during the procedure and asked the doctor if he liked looking at "butts" all day. The nurse said he did not respond. I did make another statement, but I will not put that one in writing...

I have been going to Photopheresis (blood altering process) every other month instead of monthly. Clinic visits are now every other week. The weekly shots of Enbrel have been stopped and another drug will end in three weeks.

The doctor said that I looked good and he was not concerned about the weight. One of the drugs (castor oil based Sporanox) may be causing the problem and it may be stopped in three months instead of six months.

I am doing a little more walking. We walked through Walgreen's, Target and the Dollar Tree last weekend. Since I had Photopheresis this Thursday and Friday, I decided it was best to stay home and be extra lazy on Saturday. Wednesday, my friend, Debbie, came over in the afternoon. I enjoyed having company.

I have tried to do a little more. I shopped for the exercise. For example, one day we went to the new Dollar Tree and Books-a-Million in Colonial Heights. Then we came home for lunch and went to Sam's. We were almost finished when my legs told me that I was "finished". I left Ross to check out while I "checked out" to the car for water and a rest.

On October 5, I went to the clinic, and Dr. Chung said I was doing great. He was no longer concerned about my weight because all my labs and blood chemistries were great. I did gain weight; I am up to 109...a pound at a time.

Dr. McCarty told me the following in case my "ears were burning": he would be speaking at an eastern regional conference in Maryland on November 11 and again at a national conference in February. His topic was going to be "me", and he asked permission to use the recipient/donor picture that I had given him in 2003 before the transplant. I should feel good about being the first in the nation in this clinical trial with Myelodysplasia (a blood cancer); I am also the longest survivor and totally cured. I thanked the doctor, but I am most thankful for my two sisters.

We put a small refrigerator and microwave upstairs because I have taken to waking up between 2:00 and 3:00 in the morning and being hungry. I usually have a cup of decaf tea and Colby jack cheese. I have learned not to eat Hershey's special dark chocolate during the night because chocolate on the pillow is not appealing.

Last weekend, we went to the Oak Grove Methodist Church Helping Hands' Carnival. Each year, they provide support for youth with cancer or injuries. Last year, they provided financial support for the little two-year old that had a stem-cell transplant at about the same time as mine. I had wanted to attend last October, but I was in the hospital. We went this year. This year they supported a 16 month-old boy with a rare bone marrow disease, a 17 year-old brain tumor survivor, and a 15 year-old girl injured in an automobile accident. They raised over \$4000.00 this year. Next year, I plan to provide some of my hand-made jewelry for the silent auction.

At 5:30 AM on Monday morning, Ross got in line for the flu shot. The store opened at 7:00 AM. He was number 312 out of 450 doses available. Some people got in line at 7:30 last night. I cannot get the flu shot, as I do not have an immune system. I should be able to start my "baby shots" in April of next year. It will be "baby shots" for a 65 year-old "baby".

Kimberly and Tyler arrived for the weekend. Tyler went shopping with his Poppy B. to get Kim's Christmas presents, out to lunch and then selected a pumpkin from the pumpkin patch. Kim and I went shopping. I decided not to cook this time, and Ross went out to get our dinner.

Speaking of cooking, last week, my stove decided it had a mind of its own. I put a roast in the oven at 350 degrees and went for a nap while Ross went shopping. Ross came home and smelled something hot. The oven had a mind of its own and switched to broil. We turned off the oven, but the broiler stayed on. We had to use the circuit breaker. It would have taken ten days and \$250.00 for a repair. We bought a new stove, only with a smooth cooktop and a convection oven.

I had to find a new "to do" list as the Christmas shopping has been completed, the gifts wrapped and ready to mail except for Kim and Tyler's gifts. They will be here for Christmas.

I will write again soon. Take care of yourself. Thank you for being my friend.

Love,  
Shirley

November 26, 2004

Dear Friend,

Since my last letter, I have done a little more, especially shopping for exercise!!! I have slowed a little with another bout with GVH (graft vs. host disease). I have GVH of the skin and mouth. Fortunately, the only part of my skin that hurts is my hands and feet, but that limits me in the amount of walking and using my hands for working with clay. I am back on the immunosuppressants, the ones that cause my hands to shake. No shaking yet! The GVH of the mouth makes eating difficult; it involves eating cream soups and drinking Ensure. The doctors have said that the GVH will eventually go away. My immune system and Charlotte's immune system will eventually live in harmony. I now go back to the clinic weekly and have Photopheresis (blood altering treatment) every other week. Unfortunately, I am down to 97 pounds, so weight gain is necessary. No baby shots in the near future.

Luckily, our Christmas shopping is complete and the cards are addressed and ready to mail. I am now looking forward to the next holiday. The snowman that Ross built is on the front steps and my wreath is on the front door. We will put up the LITTLE tree on the school desk in the corner tomorrow.

One nurse told me to put turkey, dressing and gravy in the blender and drink it. I became irritated at the number of blender suggestions that she gave me. Never would I try any of it. I would rather drink Ensure and Carnation Instant Breakfast milkshakes.

Scott leaves to return to California at 8:00 tomorrow morning. He arrived here last Saturday and had a working holiday. He worked here from the house on Monday, Tuesday, and Wednesday. Wednesday evening and Thursday morning, we had our Scrabble games. He thought he would beat me. Wrong!!!! He always knew that I was competitive and stubborn. It has been wonderful having him here.

I talked with both girls and they are fine. Kim and Tyler (age 6) will be here for Christmas. I am also looking forward to that visit.

Dr. McCarty did speak about me at an eastern regional medical conference on November 2. He even shared the picture of the three sisters. I told my sisters that we were now famous. He will be speaking at another conference in January and at an international conference in February. He also showed me the chapter in a recently published book about Myelodysplasia. Part of the chapter is about me. I asked for a copy when he had a chance to copy it.

If I do not write again before Christmas, have a happy and healthy holiday.

Love,  
Shirley

February 12, 2005

Dear Friend,

I checked the date of my last letter, I and realized it was dated November 26. The last couple of months were very busy. Kim and Tyler (age 6) were here for Christmas and I am not sure what happened to January.

I have done quite well, but the GVH (graft vs. host) of the mouth still exists. My mouth stopped hurting; I just have not been able to taste much. The taste buds for salt and sweets function well. My meals have consisted of apple juice, waffles (blueberry), cream soups, Ensure, roasted chicken and desserts (cheesecake, pumpkin pie, milk shakes, and peanut butter cups). I have tried other foods that I cook for Ross. The best part has been eating chocolate. My weight has remained steady at 100 pounds. I have had a lot more energy, and am generally happy with life. I have continued the blood treatments every other week. I have actually enjoyed going to the clinic as I think of the doctors and nurses as friends and family. I must wear a mask when entering the hospital, but can take it off after entering the clinic. I continue to use magic markers and to decorate each mask so they coordinate with my outfits

I had another bone marrow biopsy. As usual, while under the drugs, I talked. I entertained them, but I cannot repeat what I talked about. I was determined before the procedure to keep my mouth shut, but it did not work. I had the procedure at 11:30 in the morning and was still dopey at 4:00 in the afternoon.

More big events take place in March. I will be 65 and am very happy with the upcoming birthday. Then on March 15, I have my re-birthday number two (two years since transplant and cure). The re-birthday makes the 65 possible. I was diagnosed in June of 2000 with Myelodysplasia (blood cancer), and today there are no signs of the disease as I have a new blood system. My younger sister told me that we retire so we have more time to visit the doctors.

I have been making jewelry again and just finished crocheting a poncho. I do quite a bit of baking and take cakes to the clinic every 4 to 6 weeks. I still enjoy shopping. The only problem with shopping is that I must always purchase something.

Time for a little rest. I will write again later.

Love,  
Shirley

March 18, 2005

Dear Friend,

So far, this has been and will continue to be a wonderful month. I am now on Medicare and turned two this past Tuesday. On my second re-birthday, I called my older sister and thanked her for her gift of life (stem cells). I still go to the clinic weekly and have Photopheresis (blood treatments for GVH) every other week. All the reports have been good and so is the shopping. We have a new Kohl's department store near here, and I have already checked it out.

I went to the grocery store with Ross on Monday so I could see if there was anything new that I might be able to eat. The taste buds may be a little better, but softer foods are easiest to eat. I have discovered Sushi rice and use it in a variety of fish and vegetable dishes. Because I only weight 100 pounds, I have a feast on cheesecake and pies. Chocolate chip cookies are good if dunked in my tea. It is a good thing that I eat to live and not live to eat. I think I must live to eat chocolate.

Spring is finally here, I think - rain and snow yesterday and 60 and sun today. I did some cook-ahead foods (cheesecake, potato salad and macaroni and cheese) today as Kelli and her family will be here tomorrow and stay until Monday. I have not seen them since July. Of course, Matthew (age 9) will remember me, but I am not sure about Cameron, as he will be two in April. We bought some toys in the hope that Cameron can be bribed to come to me.

Kimberly and Tyler will be here for four days the following week. We try to plan one activity so Ross can spend time entertaining the boys (Matthew and Tyler).

Life has been fun, especially so because of good friends, family, doctors and nurses. My nurse said I should be the poster "child" for stem cell transplants. The doctor in Apheresis sang "Happy Birthday" and gave me little apple pies and peanut butter cups. I told her she was my "junque food" sister as she also thinks that chocolate is a very important food. I took the doctors and nurses in the clinic a plate of re-birthday cookies on my two-year anniversary and my birthday cake on my real birthday. I really do have a fun life. Everyone is so friendly and caring.

I do very little housework. In fact, I am doing this letter because Ross is scrubbing the kitchen floor. I usually watch TV in the evening in my favorite chair in the kitchen. Speaking of the kitchen, Ross is now making a few changes in it. He is installing additional cabinets and a work surface. I can store away all my crafty stuff and have a work surface in front of the window where I can craft and watch the busy squirrels trying to attack the bird feeders. He has already painted and installed new ceiling fixtures.

I have started to crochet again and in the last 5 weeks, I have made six ponchos and three blankets. I found the Martha Stewart poncho on the Internet and plan to make one. Both girls have asked for another poncho. Next, it will be back to the jewelry. I told a friend that there are not enough hours in the day to get everything done.

Love,  
Shirley

April 26, 2005

Dear Friend,

I am still doing well. I still go to the clinic weekly and have Photopheresis every other week. All the reports are still good.

Both girls and their families have been here for wonderful visits. I had time to spoil the grandsons. Cameron had not seen his Grandma Shirley for 8 months. It did not take him long to warm up to me. I think talking to him on the telephone helps. Of course, it helped that I could get down on the floor and play with him (it was also good that I could get back up). Matthew (9) and Tyler (7) were a pleasure, and they have not outgrown hugs. I am already looking forward to more visits.

I am still shopping!!! Yesterday, we went to Michael's and to the mall. I did walk from Hecht's to Dillard's at the other end of the mall. Of course, I had to buy something at both stores.

Two weeks ago, I taught myself to knit and in three days had completed a scarf out of boa yarn. I did buy more yarn yesterday, but have vowed to wait at least a week to start knitting again. I did crochet a Martha Stewart poncho in two days. Actually, I decided that I preferred crocheting to knitting.

The kitchen is finished and the crafty "crape" is in the cabinets. We ordered a home office chair and now I am ready to start back working with clay while watching the birds and squirrels. The advantage is that I will not have to clean the table before meals.

To keep busy, Ross has repainted the downstairs bedroom. Next, he will install laminate flooring. I must start thinking of the next project for him. He had already put new flooring in two upstairs bedrooms while I was confined to the downstairs bedroom.

More good news, I have added special dark chocolate and peanut butter back into my diet. I have finally gained a pound; up to 101. The doctors and nurses are pleased with my progress and are rewarding me by scheduling another bone marrow biopsy for May 17. The shots of Enbrel in the stomach end on May 3. I hope that they will start reducing some of the meds in the next few weeks.

Spring has arrived and the azaleas are beautiful (the old plants and the 19 new plants). Ross is the "master" gardener and I am the supervisor. I enjoy supervising!!!! Actually, I am quite bossy.

I hope all is well with you. Enjoy this beautiful spring! Enjoy life!

Love,  
Shirley

December 27, 2005

Dear Friend,

A lot has happened between April and the end of November 2005. Throughout this period, my health has continued to improve. The medical reports and biopsies are all good. I have maintained a weight of 105 to 108 pounds and remain active.

Our children and grandchildren visited us. Our big purchase was a 30-foot Coachman Motorhome. We took a trial run trip to Williamsburg to determine what and how to pack. At the beginning of October, we left for a three-week road trip to visit my sister (donor) in Arizona. We thoroughly enjoyed the trip. I would recommend a motorhome to anyone with a medical condition that affects the immune system (mine because of meds). It was nice to take our own environment with us. We knew that our lodging was germ free. I could control the food preparation. I called it "sanitation on wheels". I did call Nurse Judy on the second day as I had the need for reassurance as we were increasing the distance from the clinic. It was probably very much like a kindergartner on the first day at school.

In November, we took the motorhome to Georgia to visit children and grandchildren. This was our first trip to Georgia in over 5 years. It is wonderful to be able to travel again.

Our son visited from California in September, and we had family here for Christmas.

About a week before Christmas, I did hit another little bump in the road. I had the return of GVH (graft vs. host) of the mouth. It returns as a mouth full of blisters that make eating difficult. So, it was back to cream

soup routine. I eat breakfast and can tolerate roasted chicken for dinner. One great thing is Folger's Vanilla Cappuccino made with milk – good protein source. I have now had the GVH for 6 weeks. My doctor has sent my records to Johns Hopkin's Hospital to a GVH specialist. We are waiting to hear from the specialist, and we will probably be going there for help in planning a new course of treatment. If it is a chemotherapy treatment, I will refuse it. That treatment could cause me more serious problems than the GVH. The treatment cannot include Prednisone as it wipes out the leg muscles and increase blood sugar to the point of needing insulin. I refuse to spend my time in a wheelchair. This bout of GVH has affected eating, but not shopping and generally enjoying life.

I still stay active...shopping, cooking, crafts, talking on the telephone, etc. I am very fortunate. In March, I will be three years out of transplant. I will celebrate my 66th birthday and my 3rd re-birthday. The key to my success is wonderful doctors and nurses, family, friends, and self-determination.

I hope you had a wonderful Christmas.

Love,

Shirley

April 30, 2006

Dear Friend,

Everything is going great for us. Nothing came of the possible trip to Johns Hopkins', I definitely decided against additional chemotherapy. I felt that at my age, I did not want to deal with additional problems. I am still dealing with the GVH of the mouth, but it seems to be getting better. I did try successfully to eat peanut butter the other night. I know everything will be great when the special dark chocolate reenters my diet...still burns a little.

Scott and Renee were married in California. Unfortunately, I could not attend as I am unable to travel by airplane.

March was a wonderful month for me. I reached the ripe old age of 66 and had my third re-birthday. I am so fortunate to be here and enjoying life. I was amazed at the number of birthday cards that I received this year. So many people have stayed in contact with me since the transplant in 2003. The numerous cards may have been the result of the e-mails I sent with a "gentle" reminder of my birthdays.

We took the motorhome to Georgia at the end of the first week in April. We were able to spend a couple of wonderful days with Kelli and her family. Cameron (3) had his birthday party while we were there. After this first trip of the new year, I am ready to travel more. We may go to Pennsylvania Dutch Country, and we will be going the Eastern Shore to see the pony swim in July.

Kim and Tyler came on April 15, and Kimberly returned home on April 16. Tyler (8) stayed with us the week of spring break. Unfortunately, I had a virus and fever. My nurse told me that I had a normal person's ailment. Ross had the pleasure of entertaining Tyler with miniature golfing, trips to the park for basketball, luncheon outings and one breakfast out. I am not sure about chocolate chip pancakes and "grits".

I am planning to do some more sewing as soon as I get used to the new sewing machine. I bought a computerized one. I am still working on my other hobbies - crocheting, jewelry, baking, etc. We did put out some more plants in the yard yesterday. I must enjoy the outside plantings, as I am still not allowed to have plants in the house. I have a few "fake" ones. They do not take water and never wilt.

Well, this is one of my shorter updates. I hope all is well with you and as always, I look forward to hearing from you. Take care and enjoy life.

Love,

Shirley

September 30, 2006

Dear Friend,

Well, I just completed this letter, and the computer locked up when I tried to print it. Therefore, I had to start over again. Now the other one was good, and I had not saved it.

We have had a busy summer with two Virginia trips followed by a wonderful week here with our grandson, Matthew. We took the motorhome to Chincoteague for the pony swim, and Kim and Tyler went with us. My younger sister and her husband stopped for a visit on their way north for the summer. My cousin that I had not seen for 44 years came for a visit and a few games of Scrabble. Naturally, I won most of the games. It sure did not hurt my ego.

On September 19, Scott and Renee made me the proud grandmother of a baby boy, Kyle.

My health is fine, except for some GVH in my mouth. My blood work is great, and I am maintaining my weight at 114.8.

We will be taking a really big "trip". We have decided to downsize, and the house was listed for sale this week. This is a big downsize as we are moving into an apartment when the house is sold. It is a little difficult deciding what to keep and what to give away. The children had already made their "wish lists". They are just receiving things sooner rather than later. It is time to move, as we really do not need a four-bedroom house. By downsizing, we will not have to do yard work (I did not do any), climb stairs and all that good stuff. There are too many stairs in a tri-level. Naturally, we have been busy with painting and getting the house staged for sale – Ross paints and I stage. The house was listed on Tuesday and was shown today. We were asked to be gone between 11:30 and 12:45. I had time to do the quick five-minute drill and bake four chocolate chip cookies so the house really smelled great. When we got home the cookies were still on a plate and, the brochures for the house were on the table. Oh well, I guess the baking and the five-minute drill were just for practice.

We will be moving into an apartment complex. The apartment is on the first floor in a no pet and no smoking building. We will have two bedrooms, two walk-in closets, two bathrooms, kitchen, laundry area, and a dining and living room. The apartment is freshly painted and has new carpets. It is located about 25 minutes from here and is about the same distance to my doctors in Richmond. I can ride the bike in the cardio-fitness room and the grandchildren can use the pool. When we take the motorhome, all we have to do is lock the door and notify the office to pick up our mail. I think this is a good time for us to make this move.....work less and enjoy life more.

More later. The next chapter in my life begins after we have moved into the apartment.

Love,  
Shirley

March 27, 2007

Dear Friend,

It is a good thing that I called you, or you would not have known that we moved the day before Thanksgiving. We spent Thanksgiving unpacking. I know it has been a good long time since I last wrote to you.

I am still fine from the transplant except for some minor GVH in the mouth and the fingernails. My blood tests are great, probably much better than the average person. Back in 2000 when I was diagnosed with Myelodysplastic Syndrome, I was also checked for a slow heart rate in the 40's. At that time, the heart specialist said that if it consistently dipped into the 30's, I would need a pacemaker (ticker booster). For the past several weeks, I have had the dips into the 30's more frequently. I had made an appointment for this last Thursday, but a week ago Friday, I had a lot of vertigo and felt "not great". We went to the emergency room and I remained in the hospital until last Sunday morning (about 45 hours).

On Tuesday, I had an appointment with a Dr. Gilligan, heart specialist. The sick sinus syndrome was at the point where I needed a pacemaker. I had all the pre-op work and was supposed to check into Chippenham Hospital on April 2 to have a pacemaker. I was not worried. The doctor said I would have more energy, sleep better, etc. Usually only a local is given, but he said I could have the works....la la land here I come. I warned him that I do talk and entertain while I am "out". I cannot put my talking agenda on paper, but it is funny. I use the same story every time and remember nothing. Unfortunately, the pacemaker had to be delayed because while in the hospital, I got a staph infection in my Hickman line. Well, I finally got the pacemaker and I have more energy and feel great.

I even told a cousin that next year, I might beat him at tennis instead of scrabble!!! He told me that I could probably play tennis, but as we age, we have an increased tendency to trip over our own feet. I better just stick to Scrabble and continue to exercise my mind. As soon as possible, we will resume our travel planning. We have trips to North Carolina in June and Michigan in July. Kelli and the boys will visit in June.

We love apartment living. When more than two people (or people over 65) visit, we will just rent the guest unit that is a very nicely furnished one-bedroom apartment only two doors from us. We have the convenience of a putting green, tennis courts, work out room and in the summer a swimming pool.

I hope all is well with you. I had my fourth transplant re-birthday on March 15, so I feel that I can do whatever I want to do. I use the philosophy "because I can".

All for now,  
Love,

Shirley

December 30, 2007

Dear Friend,

It is a good thing that we still talk on the telephone. This past summer was very busy. I got the ticker booster (pacemaker) in the spring. We had to cancel our trip to Georgia because of the surgery. In June, we camped in North Carolina, and Tyler spent several days with us. He kept his Poppy B busy at the swimming pool and fishing. I found I had plenty of energy for walking.

We did make it to Michigan for our big trip of the year. We left right after the 4th of July and were gone for almost three weeks. It was the most wonderful trip down memory lane. I just had a feeling that I had to reconnect with my past, as we are not getting any younger.

We left Virginia in the motorhome and traveled to Waterford, Michigan, to see my donor and her husband. We parked the motorhome at a state park. We had a wonderful time with Charlotte and Tom. After we left there, we traveled to Traverse City to visit one of my college roommates. While in Traverse City, we toured a winery in the heart of Michigan's grape growing area and had a wonderful time visiting my former roommate and her husband on their beautiful farm. The doctor said I could taste the wine as he thought I was probably a "cheap drunk". Well, I tasted the wine and just about hit the ceiling. The wine in a mouth with GVH was a big, big burn. I really think the doctor knew that would happen as usually alcohol is not allowed with my medications. I will wait ten more years before making the request again.

After leaving there, we traveled to Saugatuck, Holland, Kalamazoo, and Battle Creek. We then arrived in my hometown of Berrien Springs, Michigan. We parked the motorhome at a KOA campground just across the state line in Indiana. While there, we went to Warren Dunes State Park, where I had spent many summer days walking the dunes and swimming in Lake Michigan. It was a very windy day, but I did a little walking on beach until the blowing sand started to sting the skin. We drove around Berrien Springs and "visited" relatives in the Rose Hill Cemetery. We also went to visit my high school friends, Bonnie and Bob. Bonnie was also a college roommate. Another high school friend, Sandy, came to lunch. I had not seen them in 40+ years. The whole trip down memory lane was very meaningful for me. I will long cherish the renewal of past friendships.

In September, we spent three days in Williamsburg, Virginia, with the motorhome. I thoroughly enjoyed the entire outlet Christmas shopping. I corresponded via e-mail with a restaurant in Williamsburg that had passed the Virginia State Health Department food inspection. They said they would cook my meal according to my wishes....no spices, no pepper, no tomato.... We had a wonderful meal one evening and went back the next day for lunch. Besides shopping, we walked around Colonial Williamsburg.

In November, we visited Kelli and her family in Georgia. After a wonderful visit, we went to Myrtle Beach. We had never been there and plan to return. The temperature was in the 70's, and we were the only ones walking on the beach. The ocean was beautiful and the air refreshing. My younger sister was also in Myrtle Beach for an art workshop, and we had a chance to visit Patti and her husband.

So much for our travels.... Scott and baby, Kyle, flew in from California for a visit. Kelli and the boys visited during the summer from Georgia. Kim and Tyler came often from North Carolina. Kim and Tyler spent Christmas with us.

There were some health issues during this time. I naturally had the pacemaker implanted. I also had another staph infection in my Hickman line and was on heavy doses of antibiotics by IV at home. I finally had the line removed and had planned to have a Smartport implanted at the same time as the removal. Well, it did not happen that way. The doctor said they could remove the Hickman, but the area would have to heal for 10 days before the implant of the Smartport. Because of my small size, there was no room to put the port. I waited 10 days and had the surgery to place the Smartport. I am skinny, so it looks like a fat button on my chest. I told the doctor that it was too bad that now I could finally go swimming, but I could not wear a bikini!!! Actually, what old woman of 67 would want to wear one.

Because of the GVH, I still have Photopheresis twice a month. I do have more energy, I am happy, and I just enjoy life. I can tolerate the lack of fresh veggies and fried chicken. I eat what I can and then drink four Ensures each day. I have increased my weight to between 114 and 118. I had to give all my size 6 jeans to Goodwill, and buy size eight. That is fine, because I love to shop. My blood tests continue to show great results. I am very healthy except for the mouth GVH. Oh, if I have not already told you, I do not have to have any more bone marrow biopsies. The blood tests tell the health story.

My advice for anyone going through a transplant would be to read everything, ask questions, stay active, and maintain a positive attitude. A person must be his or her own advocate.

Well, dear friend, I must close now. I will be sure to write again after my real birthday and before my re-birthday.

Love,  
Shirley

March 8, 2008

Dear Friend,

Well, my birthday has passed and my re-birthday is on March 15. I am 68 in real years and almost five in re-birthday years. So far, it has been an eventful 2008. I am on a self-imposed quarantine as the flu season is at a peek in Virginia. I am determined to stay healthy.

The end of January brought some discomfort. I had my Photopheresis treatments the last two days of January. The first day of treatment was quite eventful. In Photopheresis, blood is drawn in six cycles with the white cells removed and the red blood cells returned to the body. At the end of six cycles, the white cells are treated and returned to the blood stream. At the end of the first cycle, I felt quite bad and finally told the nurse. My throat was dry, it felt like my mouth was swelling, and I had trouble swallowing and breathing. My blood pressure went to 87/35 and I turned the red color of the hazardous waste bin. The three nurses sprang into action. Up went my feet, down went my head, an ice bag was placed on my head and I was infused with fluids. I finally stabilized and the treatment was aborted after four of the six cycles. Well, I went back the next day, and the same thing happened at the end of the first cycle. The only difference was that I reported it as soon as I started feeling bad. They stopped the process. They reset the machine and started over. In the meantime, a doctor came in and watched. Well, at the end of the first cycle, it happened again. They went through the same process, up with the feet, down with the head, ice, and fluids. The doctor had the treatment aborted. He immediately started checking patient records. That was on a Friday. He called on Monday morning, to let me know that the common denominator was the bolus dose of Heparin. He called the FDA, Baxter Healthcare, and the CDC. The Virginia State Health Department visited the hospital on that Wednesday to check patient records and filed a report with the CDC. The result was a further recall by Baxter Healthcare and the inspections of the supplier in China. I am naturally anxious to hear what the contaminant was. I have been following the reports on the Internet and in the paper. I sent letters to our district representative and senator in the United States Congress. They did not acknowledgement of receipt of my e-mails. Hmmm...future voting decisions.

Kim and Tyler have been here for a visit. We are busy planning our spring travel. Ross will have the motorhome ready for travel by the end of the month. In April, we will travel to Savannah, Georgia. We have never been there. Then we will continue on to see Kelli and her family in Marietta, Georgia. We plan to travel to Michigan to see my older sister in July. My younger sister will also be there. It will be a sisters' reunion. Then in November, it will be back to Georgia, and Myrtle Beach, South Carolina. We will plan additional trips based on the price of gas!!!. A motorhome is a gas-guzzler.

This is a brief picture of the last eight years. Besides being a five-year transplant survivor on March 15, it will have been 2810 days since I was diagnosed with Myelodysplastic Syndrome and 1826 days since my transplant. Before the transplant, I had 125 units of blood. Since the transplant, I have had 162 Photopheresis treatments, two ports and two Hickman implants in my chest....all removed except for one port. I also have a pacemaker....the beat goes on.

Now the better stuff....I have four grandsons – two since transplant. I have had an additional 8+ years of marriage for a total of almost 46 years. We bought a motorhome in the summer of 2005, and we have traveled through or to West Virginia, Pennsylvania, Ohio, Indiana, Maryland, Michigan, North Carolina, South Carolina, Georgia, Tennessee, Oklahoma, Texas, New Mexico, and Arizona. Naturally, some of our trips have been in Virginia. We have visited many important people that have touched my life from family to high school and college friends.

I still use a cane. I actually own four of various designs and colors. Hmmm...five years, maybe it is time for cane number five. I have not decided if the cane is a necessity, security or a fashion statement. I do need the cane for a few hours after the Photopheresis treatments. I try to match the cane to my outfit. I still decorate the mask that I must wear in the hospital until I arrive in the clinic. The mask also matches the outfit. I am maintaining a weight of between 114 and 118 pounds. The blood counts are still spectacular. No "baby" shots yet as the treatment for the mouth GVH continues.

I continue to enjoy life. Yes, there have been some little bumps in the road, but no "potholes" since the spring of 2004. I feel very fortunate to have been part of a clinical trial and to be a "survivor". I hope sharing my

experiences will help others. I am now up-to-date on my letters. I will send another one after our travels this spring, summer and fall.

Yes, we will keep in contact by telephone and e-mail. Thank you so much for being my friend.

Love,  
Shirley

**September 1, 2008**

Dear Friend,

We have been extremely busy since my last letter in March. I ended my self-imposed flu season quarantine and resumed enjoying myself.

Well, I did receive some responses from my three severe reactions to the tainted Heparin in January. I have heard from several lawyers that I do not qualify for a class action lawsuit, as fortunately I am still alive. I did receive two very good responses from Senator Jim Webb of Virginia. He actually sent my first letter to the FDA. The second response included a copy of the letter that the FDA (actually they even used my name in the letter) sent to him in response to his inquiry on my behalf. Because of his kindness and taking the time to help me, I may even vote for him when he is up for re-election.

In April, we traveled to Savannah and spent several days sightseeing. We then traveled to Marietta, Georgia, to visit with our daughter, Kelli, and her family. We went back to Georgia again in May for Matthew's Make-A-Wish Luau before their trip to Hawaii. Kim and her family joined us in Georgia.

In May, I took part in a course offered to transplant nurses at the Medical College of Virginia. I spoke (without notes, I had them but did not use them) for 10 minutes about my journey with Myelodysplasia. Even with my experience as a Coordinator of Gifted Education and giving presentations, I was extremely nervous before speaking. Within two days after the class, this story on the web was read more than 20 times. Must have been the nurses! I will be taking part in the next class in November.

On June 19, we moved into a new apartment in Midlothian, Virginia. This is a larger apartment with a more open floor plan. It is also a gated community. We have a first floor apartment. The best part is instead of 30 minutes from anything, we are now two minutes from everything. We are two minutes from Stein Mart, Kohl's, Barnes & Noble, Michael Crafts, and the grocery stores. Now this is a real gas savings. We are now 30 minutes from the hospital instead of 15 minutes, but we only make that trip 3 times a month. Kim and Tyler stayed here for several days and helped with the move. We rewarded Tyler's hard work with crab legs and a movie date with his mom.

In July, we took a two-week vacation to Waterford, Michigan and spent 5 days with my donor sister and her husband. We had wonderful time. Naturally, we traveled in the motorhome. We had great weather except for one big, big storm in Ohio. It occurred in the late evening. There were tornado warnings, but all we felt was a little rocking of the motorhome. Whenever there is a storm, I react like Chicken Little – the sky is falling!

In August, Kim and Tyler (10) spent a weekend with us. She drives from up from North Carolina when there is a break from all of Tyler's sports.

We have started to reduce my Tacrolimus (immunosuppressant). We are reducing it gradually as I previously had to restart medication because of increased GVH. This month, I am down to 2ml twice daily. We are dropping 1ml twice daily each month. One doctor is checking to determine if there is a possible rebound reaction as my blood pressure increased at the end of July. We have that under control with 5mg of Norvasc daily. The most common side effect of Norvasc is dizziness that occurs mainly in the evening. I may have mentioned before that if a medication has a side effect, I usually have it.

This month brought the end to taking Coumadin. I did not need it as the lines that had little clots on them had been removed a year ago. I was not on a therapeutic dose, just a maintenance dose. I questioned the taking of "rat poison" since the Hickman Catheter was gone. In addition, I no longer need to have the monthly breathing treatments with Pentamidine because the Tacrolimus levels are so low. Pentamidine protects the lung of an immune suppressed system from a deadly pneumonia. I just had my last 20-minute breathing treatment on August 27.

Scott and his family will be arriving from California for a visit on September 13. I am hoping that Kyle (almost 2) will remember me. I have talked to him on the phone. He has communicated with me in his own language! The will fly back to California on September 18. I hope that what they say about children keeping a person young is true. Hmmmm...a two-year old boy, a ten-year younger grandmother!

Generally, I am doing well. I am hopeful that in another six to seven months I will be finished with the medications and finally get my "baby" shots. I still have GVH of the mouth so will continue with the twice-

monthly Photopheresis treatments. I am just happy that the "good" heparin is in use with the treatments. I have had a few little bumps in the road, but nothing major. I have been following the progress of several other MDS patients through the CarePage web site. I have even offered a little "motherly" advice. I feel truly fortunate to be able to share my experiences with others.

I hope all is well with you. Thank you for being my friend. I will either call or write again soon.

Love,  
Shirley

**December 20, 2008**

Dear Friend,

We took one more trip in October before we had the motorhome winterized in preparation for traveling again in March. In October, we went back to visit family in Marietta, Georgia, and then to Myrtle Beach for several days. Last year Myrtle Beach was warm in November. Not this year, we were there during a three-day cold snap. We still enjoyed ourselves. We just dressed in layers and used the heat at night.

We attempted to stop the immunosuppressant drug, Tacrolimus. I took my last (!) dose on October 22. Oh well, I had to restart the drug on December 6, as the GVH in my mouth got worse. There is still a little sibling rivalry from the stem cell transplant. Other than the GVH, I am doing quite well.

This next part is unusual because I do not usually spend much time talking about my family. I feel a need to share with you the latest news about our grandson, Matthew. In 2000, just before I was diagnosed with Myelodysplastic Syndrome, our grandson at age four was diagnosed with a craniopharyngioma and had his first brain surgery in April of 2000. Radiation followed in September of 2000. By January 2006, the tumor cyst had increased in size and he had his second surgery in late February. A third surgery was performed in November 2006, with more radiation in January and February 2007. This year has carried Matthew through six additional surgeries both at Le Bonheur hospital in Memphis and Scottish Rite Hospital in Atlanta. The Ommaya Reservoir was placed to periodically drain fluid from the cyst. After the September surgery, the nonmalignant tumor converted to a malignant tumor. Matthew will turn 13 on January 3, 2009, and will then begin chemotherapy. I mention all of this because I just want to share with you that Matthew is my role model and my hero. Matthews has experienced some vision loss, but has maintained his strength and his positive outlook. When I talk to him on the phone, I ask him how he is doing. He always responds with "great". He has handled more in his thirteen years than most people experience in a lifetime. Matthew was approved to receive a wish from the Make-A-Wish Foundation this year and he had his family had a wonder family experience in Hawaii. He was able to swim with the dolphins, visit Pearl Harbor, and experience a luau and snorkel in Hanauma Bay along with many other wonderful adventures. Matthew has taught me to maintain strength and a positive attitude. He has shared his love for art and music with me. He has shared his love for life with me. We have shared our own battles with cancer since 2000. It is almost 2009, and we are both still going strong. We will survive 2009 with many good experiences.

I have a second role model. That person is our oldest daughter, Kelli. She has been the "glue" that holds the two generations together. She is a very caring and strong individual who has put both us first in our journey through and battle with cancer. She puts her family first, but still has time to help others. She is a very giving person. I feel extremely honored to have her for a daughter.

I have just one further request, dear friend. Please visit Matthew's Carepage. You have followed my journey so lovingly, please follow his journey at <http://www.carepages.com/carepages/MatthewJTTracy> I will try to send you another letter in the first part of 2009.

I hope you have a wonderful holiday season with family and friends. Take time to count your blessings. Hug someone special.....always a hug for children.

Love,  
Shirley

**April 5, 2009**

Dear Friend,

Wow! It has been a long time since my last letter. I will begin with a brief update on my medical status. The GVH of the mouth and eyes continue to exist. I do fine with the GVH of the mouth as long as I can remember that there is more to life than eating. I eat what I can tolerate and then drink four Ensures each day. It seems to work for me. Since I have a list of everything I can eat, I designed a brochure for the clinic about foods that easily tolerated based on my own experiences. I even included a few recipes. For now, eye drops, low lighting, and sunglasses help the GVH of the eyes.

We bought an elliptical cross trainer to help me increase muscle strength in my upper legs. I thought the weakness was permanent and caused by Prednisone. Dr. Chung said the weakness did not have to be permanent. Well, we got the cross trainer .....now that is work. At first, I could only exercise for two minutes, but I have increased it to 15 minutes. Stairs are becoming easier to climb. It is much easier to get in the car. Next a marathon!

Kimberly and grandson, Tyler, spent Christmas with us. It is such a joy to have family spend their holiday time with us. They came from North Carolina to Virginia by train. This eliminates the holiday traffic. They came with one packed suitcase and returned with two. Space bags are great for packing after Christmas.

In March, I reached two goals. I turned 69, and I became a six-year stem cell transplant survivor. I accomplished my goal through my own stubbornness and a little help from the medical profession. It did not hurt to have supportive family and friends.

In March, we traveled to Georgia to visit our daughter, Kelli, and her family. I was happy to spend time with our grandchildren, Matthew and Cameron. Kimberly and Tyler joined us at Kelli's home.

Matthew had chemotherapy for the malignant brain tumor. I cannot go into detail about his condition in this letter as I have difficulty putting my feelings into words. Please, please read about his journey and supporting him by going to <http://www.carepages.com/carepages/MatthewJTracy>. By logging in and creating your password, you will be adding to the growing community of those who care. Matthew continues to be my role model. He continues to fight a courageous battle and is an inspiration to all who know him.

After leaving Georgia, we traveled to Orange Beach, Alabama. While there, we had a wonderful visit with a high school friend and her husband. I had not seen Linda in 47 years. We played together as pre-school children, graduated from high school together, and Linda cut the cake at my wedding in 1962. Several years ago, we renewed our friendship via e-mail. Yes, we still like each other.

After a couple of days in Alabama, we continued in the motorhome to Fontainebleau State Park, just north of New Orleans. We drove the previously towed car to Slidell where we met my second cousins for the first time. We had communicated via e-mail as we worked on our family trees, but had never met. After meeting, sharing family information, and a great home-cooked meal, we felt that we had always known each other.

We drove across the 24-mile Lake Ponchartrain Causeway into New Orleans. We set the GPS for a location in the French Quarter. We took a carriage ride, did our own walking tour, had coffee and beignet at the Café Du Monde, and walked over the trolley tracks to the Mississippi River. We did not stay to experience the nightlife, as it would have been past my bedtime. Therefore, I could not get drunk (against doctor's orders) and dance on the tables. We had a great time. I wish we could have stayed longer.

We have planned another trip to Georgia. We will be returning there in May and will be staying for six days. I will be sending another letter in June. Remember to visit Matthew's carepage.

Thank you for following our journeys. Continue to count your blessings. Hug someone special each day.....always a hug for children.

Love,

Shirley

NOTE:

The Myelodysplastic Syndrome is gone, but the journey continues. It continues through the healing process and the rebuilding of my system. I do not expect any cell rejection. I am so thankful for my friends, family, the doctors (especially Dr. John McCarty, Dr. Harold Chung, and Dr. Yogesh Gandhi) and all of the nurses at the MCV Bone Marrow Transplant Unit (clinic and inpatient), Dr. Gandhi's nurses, and the nurses on the second floor east at John Randolph Medical Center. I am so thankful for having Judy Davis as my former nurse, my "therapist", and my continuous friend. To the list of doctors, I must add Dr. Gilligan and Dr. Toor. I have great respect for the Medical College of Virginia Pathology (Apheresis) Department, especially Dr. David Wilkinson, Dr. Richard McPherson, and Dr. Susan Roseff. I am also thankful for Jenni Anderson and her staff of nurses in Apheresis.

If you are a transplant patient, be an active advocate for yourself. It is important to follow the rules. Be sure to ask questions about everything; become an expert. Research everything on the Internet, as you can never know too much. Yes, listen to others, but always remember you are the final decision-maker. Do not leave anything to chance. Have an unrelated confidant with whom you can share your joys and fears. Double-check all medications and have an understanding for their purpose and their side effects. Do not allow "pity parties" to last more than five minutes as they are really a waste of time and make your eyes hurt. Do not shake hands, just become a hugger. Do not touch doorknobs; let others open the doors. Wear latex gloves when handling raw meat and vegetables. It is always good to carry a clean latex glove in your pocket. You

never know when you will need one. Wash your hands frequently and constantly remind family members to do the same. The most important thing to remember is to count your blessings. It sometimes helps to list them. Keep a positive attitude. One of my best pieces of advice is to eat peanut butter, special dark chocolate, and Colby-jack cheese.

My story is not complete. I continue to feel good, just tired. I have reached the age of 68 and plan to be around for another ten years. I hope that what I have written will help others in dealing with the little known (in 2000) blood disorder, Myelodysplasia.