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Stories from Stem Cell Transplant Recipients

- **NATHAN GUILLIOUMA**

Nathan's lupus was diagnosed at the age of 15. At that time he did not appear to be sick. He was an active, normal teenager, playing both football and baseball. The only sign of lupus was a rash that appeared on his face occasionally. He also had itching arms, and we assumed he was just sunlight-sensitive due to his light skin complexion.

In October 1997 we took him to a dermatologist who took one look at him and said it could be lupus. Further tests were done, and a second opinion was sought from a rheumatoid arthritis doctor. All tests came back positive. Nathan had active lupus with kidney involvement. Chemotherapy was started for nine months in 1998, but by October of the same year Nathan started to get weaker, with little to no energy, joint pain, and numbness in fingertips and feet. He became very anemic, lost his appetite, and was not able to sleep well at night. By February 1999 he had developed severe diarrhea, and on March 7, 1999, we put him in the hospital.

During that time Nathan had his first seizure. We were told that his whole central nerves system was now being attacked by the lupus. The doctors in Canton, Ohio, gave us little hope in his prognosis and told us there was nothing more they could do to save his young life ---- except for Dr. Margaret Kobe, an infectious disease doctor who told us about the bone marrow transplants being done at Chicago's Northwestern Memorial Hospital by Drs. Ann Traynor and Richard Burt.

We were in Chicago for about eight weeks when Nathan received his transplant on May 18, 1999. Almost a year later, Nathan is doing very well. He is back at school and doing the normal things that teenagers do. A month after he returned from the hospital he said to his sister, 'Since I had the transplant, I have no aches or pain in my body, and for once I actually feel really good!'

-Rebecca, Nathan's mom

- **KATHY HAMMONS**

Twenty years ago, when I was 19 years old, I was diagnosed with lupus. My disease was progressive and had accelerated to a course that was threatening my life. Lupus was destroying my lungs, heart, and brain. Eventually, I developed acute lupus pneumonitis, lupus pericarditis, vasculitis on the brain, central nervous system involvement, and lupus pancreatitis. I failed to respond to all conventional therapies, including high dose prednisone, solumedrol, 17 monthly treatments of Cytoxan, and eight months of oral Cytoxan. I was on 24-hour supplemental oxygen. Nothing was working. The lupus was still aggressively destroying my organs. In June 1998, only 12 percent of my lung capacity was still functioning.

In 1999, 5,000 people died of lupus. I was not one of them. Dr. Richard Burt and Dr. Ann Traynor performed an autologous stem cell transplant on me. Going to Chicago to have the stem cell transplant has changed my life forever. After enduring 20 years of suffering from lupus and the side

effects of the medicines, I'm in complete remission. I had severe life-threatening lupus that was not responding to any other treatment, and I was expected to die. The stem cell transplant saved my life. I'm now alive, free of all lupus drugs, have all of my natural organs, and am living a normal life. I have no traces of the disease and I no longer need supplemental oxygen. I'm able to go on walks, and even bike rides with my son. I'm back to doing volunteer work in my community and am busy trying to establish a network to help other transplant patients with the costs of relocating to a transplant center.

-Kathy

• **HEATHER A. MARKEL**

When I was 10 years old I started having traveling joint pain throughout my entire body. At 11, it was like I had the flu that would never go away. Shortly thereafter, I was officially diagnosed with lupus. The next 13 years was like being on a roller coaster. One day I felt wonderful, the next I was in a coma for a week. I missed a lot of my childhood fun since I was not allowed in the sun and was physically unable to play sports with my friends. Every time I got the slightest cold I was afraid I'd end up in the hospital. Every year I missed time in school because I was in the hospital for one reason or another. I was there so much, they started to feel like my second home. Life was really tough with all of the restrictions, medications, treatments, and side effects.

When I was 24, I found out about a new treatment. Up to that point, my doctors and I had tried every treatment available, but nothing worked! The stem cell transplant was my last hope and I never had any reservations about going through with it.

Although there were unexpected side effects, it was all worth it in the end. I feel like a completely different person. I am just over three years out now and there is no sign of lupus. I went from having congestive heart failure and kidney failure, to my heart and kidneys going back to perfect function. I am now on a low dose of one blood pressure medication, which is a great difference from all the different medications I used to be on. For the first time I can do anything I want without the worry of getting sick or hurting myself. I even get over colds or whatever else comes my way without making a trip to the emergency room. I feel like I finally have my life back.

-Heather

• **LIZ MAUN**

My daughter, Liz, was 15 years old when she was diagnosed with lupus. She had led a normal, healthy life with no unusual illness, until the summer of 1997. She began not feeling well, and had lower back pain. The pediatrician suspected a kidney infection. Within two weeks of the first symptoms, Liz was in intensive care with failing kidneys, respiratory failure, and heart murmur. Liz spent the first eight days in the Intensive Care Unit in a drug induced coma, receiving massive doses of Cytoxan and prednisone to try to bring the lupus under control.

Liz spent most of two months in the hospital, receiving Cytoxan, prednisone, kidney dialysis, plasmapheresis, and blood transfusions, not to mention a mountain of drugs for all the other complications and side effects. We dealt with high blood pressure, anemia, blood clotting, bladder clotting, and continual respiratory and kidney problems. The future of our only child's health was not very optimistic. Attending physicians were not sure how long the lupus could be kept in control, if at all. We were told to expect recurring bouts with more and worsening involvement.

But, through the perseverance and diligence of Liz's rheumatologist, we learned of the stem cell replacement being performed at Chicago's Northwestern Memorial Hospital.

Two and a half years have passed since Liz received her stem cell transplant. Within the first six months her strength improved rapidly. Her involved organs began to respond and rejuvenate, much to the delight of her physicians and her family. She was strong enough at about eight months to have resumed most of her normal activities, and take on a part-time job and summer school.

At this time Liz has been taken off the mass of medications and is down to two. She still needs help to control some kidney and heart functions, but we hold hope that at some future time these, too, will be terminated.

To look at my daughter today, it would be hard to believe she was so close to losing her life to this disease called lupus.

-Mick, Liz's dad

• **ANJALENE PETSALIS**


I was diagnosed with systemic lupus in August 1995, without a clue as to what this disease was all about. It did not take long to find out. I remember Christmas 1997 as being one of the worst holidays I ever spent. By then, I had damage to my lungs, intestines, stomach, liver, and kidneys. I was on oxygen and took over 35 pills a day, among them 80 mg. of prednisone. My doctor told me that I had failed all treatment and that he did not have anything else to offer me. The lupus had taken control. No matter how hard I tried to fight, it was a losing battle. The stem cell transplant was my last hope.


Before the transplant in February 1998, I had no quality of life. My days were spent in a chair, just trying to survive. Today, I have lots of tomorrows I look forward to living. The lupus is controlled and I am concentrating on healing the damage that has been left behind. I least I have a fighting chance now.


I serve on the Board of Directors of the Oklahoma Lupus Association and as facilitator for a local lupus support group. Now I am helping newly diagnosed patients to deal with that question 'What is lupus?' My degree in Education is finally being used as I tutor students in my home. I am very grateful to Dr. Ann Traynor and Dr. Richard Burt for giving their attention to lupus research. The efforts have saved my life.

-Anjalene

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