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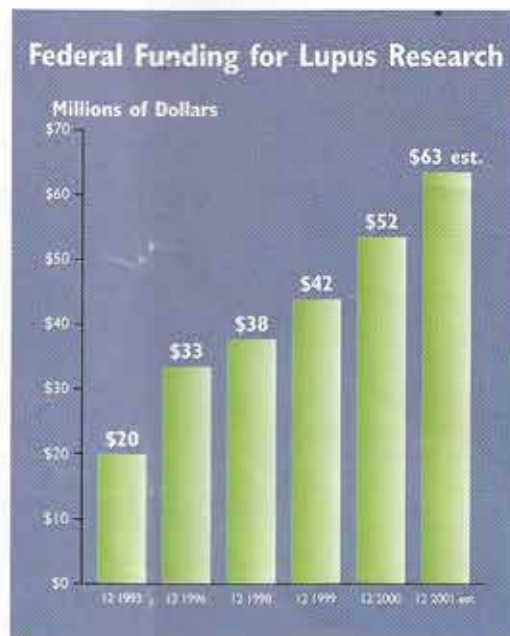
Lupus Foundation of America— Your Key to Lupus Research Funding

\$10,000,000 Increase This Year!

Federal funding for lupus-related medical research in 2000 has increased \$10 million dollars over the amount allocated in 1999. The National Institutes of Health (NIH) will spend approximately \$52 million dollars this year to support lupus studies, compared to \$42 million the previous year. This amount represents an additional \$3 million dollars over what Lupus Foundation of America (LFA) officials previously had estimated the NIH would allocate for lupus research this year. If the trend continues next fiscal year, LFA officials estimate funding could reach \$63 million, a three-

fold increase over what NIH allocated for lupus research in 1993 when the LFA began an intensive effort to boost federal funding for the disease.

The combined efforts of the LFA, its 62 chapters across the country, and more than 3,550 e-advocates, have succeeded in greatly raising the visibility of lupus as an important health issue. The NIH is the agency charged by Congress to lead the federal government's research effort. The NIH is the largest single source of funding for lupus medical research in the world and spends more to support



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\$1 Million for Lupus Research Added to California State Budget

When Joyce Thompson-Pierce, President of the LFA, got her chapter involved in having April 1 proclaimed as Lupus Alert Day in California, little did she know what the outcome would be, three months later! This is her wonderful story of the latest success of the LFA, Northern California Chapter.

In March of this year we began using the Lupus Alert Day manual that LFA Vice President of Advocacy and Communi-

cations Duane Peters sent to each chapter. Following each step in the manual, we wrote to our state and national government officials asking for proclamations to be passed to declare April 1 as Lupus Alert Day.

The upshot at the state level was that Senator Monteith responded that he would support this issue and start the ball rolling. He also was sure that Assemblyman Lou Pappan would introduce it at the assembly, as Assemblyman

Pappan's wife had passed away from complications of lupus in March, just as we started our campaign.

Well, the proclamation passed unanimously! This was a red letter day, with many of the members of the Senate and the Assembly giving personal testimonies about how lupus had affected their lives or their staffers' lives.

During our ongoing talks with

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Exceptional People: Stem Cell Transplant Recipients

From Lupus News, Summer 1997: On June 7, 1997, Northwestern University Medical School announced that a new treatment for lupus, developed at the University, had resulted in significant improvement for one critically ill patient. The treatment involved stem cell transplantation, a very high-risk procedure which will be approved by the FDA on a case-by-case basis. In verifying the news...Richard Burt, M.D., Director of the Allogenic Bone Marrow Transplantation program at Northwestern... continuously and carefully used the term "remission" rather than "cure."

Three years later, there are success stories to share, including Heather Markel's, who was that critically ill patient in June 1997.

NATHAN GUILLIOMA

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 to look forward to living. The lupus is controlled and I am concentrating on healing the damage that has been left behind. At least I have a fighting chance now.

I serve on the Board of Directors of the Oklahoma Lupus Association and as a 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. Their efforts have saved my life.

—Anjalene

Understanding Stem Cell Transplants

Stem cells are prototypes for all blood cells, including white blood cells which are part of the immune system. Stem cells found in the bone marrow and circulating in the blood stream are known as *peripheral stem cells*. This is how the process of stem cell transplantation works:

1. Blood is withdrawn from the patient through a needle in the arm, similar to an IV.
2. The same blood is sent through a cell separation (apheresis) machine to extract stem cells.
3. Blood is returned to the patient through another IV needle.
4. This part of the process may take several sessions since there are only a small number of stem cells circulating in the blood at any given time. Growth factor may be given at the time of stem cell harvest to increase the number of cells extracted at each session.
5. The stem cells are frozen after extraction.
6. Next, the patient receives chemotherapy drugs to completely suppress the immune system, which destroys the abnormal immune system cells of lupus.
7. The stem cells are given back to the patient by IV, often with growth factor.

The hope for people with lupus is that the immune system calls will regenerate normally, without the antibodies to "self" that characterize the overactivity of the lupus immune system.

Stem cell transplantation is an attempt to try to cure lupus. Early results have shown remission in disease that has failed all other treatments, but it is unknown if patients will eventually relapse. But, as these former patients testify, it has changed their lives.