

NFT FACES

National Foundation
for Transplants

Bone marrow recipient meets British donor

Susan Grant is celebrating her 10th “birthday” this year. She received a lifesaving bone marrow transplant in 1998 and met her donor for the first time in November.

When Susan started a new job in the 90s, she was unable to afford proper health insurance because of a diagnosis with melanoma the previous year. She managed without the insurance, until she was diagnosed with chronic myelogenous leukemia (CML). Her only hope was a bone marrow transplant.

A search through the National Bone Marrow Registry located several candidates who matched on six different levels.

The final step was testing for a component of the DNA, but the donors refused to take this step, despite being perfect matches in all other areas. Susan extended her search internationally and found three matches in the United Kingdom, all willing to undergo the DNA testing. Out of those matches, one turned out to be the perfect match – matching in all seven areas.

Peter Andrews lives in Reading, England and had been on the bone marrow registry for six years before he got the call about Susan. Without hesitation, he agreed to help. Susan received Peter’s bone marrow on November 25, 1998 at Virginia Commonwealth University Medical Center.

In November 2008, Peter and his wife flew to Richmond, VA to meet Susan and her family.

“Meeting Peter is a dream come true,” said Susan. “I’ve kept a photo of Peter and his family front and center on my mantel for years now.

When I look at it, I’m reminded that a complete stranger gave me back my life, and I’m grateful beyond words.”

Susan’s transplant cost more than \$100,000, and she had to raise at least \$25,000 before the hospital would even consider proceeding. With NFT’s help, Susan raised nearly \$140,000 for her transplant and follow-up care.

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Letter from the President

Dear Friends,

I'm pleased to share the latest issue of NFT Faces with you, and I hope you find it helpful.

We celebrated our 25th anniversary in 2008, and NFT has truly flourished since its humble beginnings. This has been a banner year for us, and we expect 2009 to be another great year for NFT.

Last year, NFT provided nearly \$2.2 million in assistance to transplant patients, including more than \$1.6 million in direct patient care. We currently work with more than 800 patients, offering guidance and compassion along the difficult road to transplantation. In 2008, we experienced record growth in the number of new patients assisted, increasing our patient load by 65 percent!

To better serve our patients, we streamlined our fundraising program by assigning fundraising consultants to specific regions of the country. This approach helps us operate more efficiently in terms of service and support to our patients.

We have incorporated a new element to our mission at NFT, and we are excited to begin proactively promoting and educating others about the critical need for organ donors. We hope you'll join us in the NFT Transplant Challenge, as we seek to add 100,000+ individuals to the organ donor registry.

These are just a few of the advances we've made at NFT, and there are many more to come in the near future!

Sincerely,

Jackie D. Hancock, Jr.
President and CEO

*NFT empowers transplant patients
to create futures with hope.*

How much does an organ/tissue transplant cost?

These costs are estimates and include follow-up care and medications for 180 days post-transplant. Transplant patients typically require a lifetime of costly follow-up care and medications, which are not calculated in these estimates. Please note that costs vary based on the transplant center and health coverage.

Heart:	\$790,000	Intestine:	\$1.1 million
Lung:	\$450,000	Cornea:	\$20,000
Double Lung:	\$650,000	Heart/lung:	\$1.1 million
Liver:	\$530,000	Kidney/heart:	\$1 million
Kidney:	\$260,000	Kidney/pancreas:	\$440,000
Pancreas:	\$275,000	Kidney/liver:	\$760,000
Bone Marrow:	\$300,000 to \$675,000		



Cover Story: (Continued from page 1)

Bone marrow recipient meets British donor

"I could not have had the transplant without NFT's help," said Susan. "I never would have known how to raise that much money on my own, and it was encouraging to know the staff was there for questions, advice and help along the way. NFT is a trustworthy organization with a competent, compassionate staff. I thank God for the invaluable work they do."

Check us out online!

At NFT, we've embraced technological advances and are encouraging patients and volunteers to do the same.

We recently created a blog, where you can view our new video and read weekly updates about the latest happenings at NFT. We also have presences on Facebook, MySpace, Transplant Café and Twitter.

Do you have your own Web site? Let us know – we enjoy keeping up with our patients! If you're interested in creating a personal Web site, we'd be happy to help you get started. Please e-mail ejoyner@transplants.org for more information.

Check out our blog and leave us a comment! You can find links to all our other Web sites on the blog: <http://nftblog.blogspot.com>.

Accept the NFT Transplant Challenge!

When we went to print, there were 101,204 patients on the national transplant waiting list. As you read this, the number has increased. In fact, a new patient is added every 11 minutes. Sadly, the number of patients waiting far outweighs the number of transplants performed each year.

Did you know that only 35% of Americans are officially registered as organ donors? At NFT, we're trying to change that. Our goal is to sign up 100,000 individuals in 2009. Will you join us?

Please visit www.transplants.org and click on the NFT Transplant Challenge logo. The Web site will walk you through the steps to get registered. It's that easy!

As part of this challenge, we encourage you to consider making a donation to NFT. Our goal is to raise \$100,000 to represent each patient on the waiting list. Every dollar makes a difference! The money raised will be used to help transplant patients across the country and to educate Americans about the dire need for organ donors.

Will you accept the challenge? Visit us online today!

TRANSPLANTS.ORG



**TRANSPLANT
CHALLENGE**

2008 Transplants

January

Dennis Dye – liver
Vincent Manglona – liver
Richard Miller – kidney
Shauntia Smith -- kidney
Jeff Tysinger – double lung

February

Rick Armbrecht – kidney
Leslie Bowen Olson – bone marrow
Bryan Sargeant - liver
Preston Tomblin – heart

March

Robert Brown – kidney
Robert Evers – liver
Michael George – stem cell
Sherry Hagerman – double lung
Nellie Penner – double lung
Jean-Pierre Zeugin - liver

April

Scott Evans – kidney
Nicholas Gilley – kidney
George Oakes – bone marrow
Douglas Sanders – kidney
Jamie Starks - kidney
Chris Testino – bone marrow

May

Victoria Chavez – stem cell
Billie Hunt – liver
Nicole Mausteller – bone marrow
Lakisha Melvin – kidney
Laurie Mounsamrouath – bone marrow
Dennis Privett - heart
Delbert Spriggs - kidney
Johnie Watson – liver

June

Terri Dale – limbal stem cell
Jamel Hutton – bone marrow
Susy Ross – kidney/pancreas
Ed Streck – liver

July

Kristopher Gibbs – liver
Demetria Valenzuela – kidney

August

Simon Attle* – liver/kidney
Marvin Hammontree – lung
Shawn James – kidney
Donna Miranda – heart
George Oakes – bone marrow

September

Heather Brenner – liver
Frank Lippay -- heart
Chris Townsend – kidney

October

Colleen Bolander – bone marrow
Susan Damron – liver
Larry Facemyer – small bowel
Karin Featherston – heart
Danice Hurt - heart
Rebecca Jones – liver
Ridge McCall - heart
Julie Werner* – multi-visceral

November

Kendall Chadwick – liver
Shirley Craig – heart/lung
Paula Debnam – kidney
Roseina Hester – double lung
Charles Johnson – bone marrow
Reginald Lemaster – bone marrow
Jay Menhennet – kidney
Brad Stauffer – bone marrow

December

Sandy Brown – kidney
Charlotte LaBarge – kidney
Zoila Mora – bone marrow
Sherai Onibasa* – kidney
Eric Savage – bone marrow
Barbara Sledge - kidney
Brittney Smith – kidney
Kathy Suher – stem cell

**We're sad to say these patients lost their health battles after receiving their transplants.
Our thoughts go out to their families.*



The Holston family was all smiles on Christmas, thanks to a generous family.

Denver family provides holiday assistance to NFT patients

For two NFT families, the holidays were a little brighter this year. Shortly before Christmas, a Denver-area family contacted NFT with a generous offer. In lieu of exchanging gifts, the family opted to use that money to assist two families in need.

The donors, who wish to remain anonymous, have a family member – an NFT patient – who received a transplant several years ago. They recalled how difficult the holidays were for her family, when medical bills were significant and gifts for children were not an option. The family requested that the money be specifically used for holiday gifts for families with young children.

Wess Holston is 29 and suffers from uncontrollable diabetes, often confining him to his bed. He cannot be left alone, as changes in his blood sugar levels could cause a seizure. He desperately needs a pancreas transplant. Wess longs for the day he can spend quality time with his wife (and high school sweetheart), Katrina, and their six children, who range in age from 3 to 12.

Ridge McCall turned 3 in December. Born with congenital heart defects, he received a heart transplant in October. He has faced many complications since the transplant, but he is slowly recuperating. He and his mother, Crystl, lived in St. Louis for several months as he awaited the transplant, while his father, Adam, remained in Nebraska with Ridge's two sisters. The family's financial burdens forced them to sell their home and cars, and Adam lost his job after missing too many days to be with Ridge.

The Denver family's generosity enabled the Holstons and McCalls to enjoy the holidays during a difficult and stressful time. Both families were very touched by this act of kindness and offer their sincere thanks to these anonymous donors.



NFT's founders: Liz Hull, Elise Waldheim and Mary Clouse

NFT Turns 25!

As we celebrate our 25th anniversary, we're taking a little stroll down memory lane to reflect on how far we've come.

NFT was established in 1983, in Memphis, TN. Originally named the Liver Organ Transplant Fund, the organization was founded by three caring and compassionate women after they read about a young girl who needed a liver transplant but could not afford the procedure. These women – Mary Clouse, Liz Hull and Elise Waldheim – worked hard to raise funds for the transplant and related expenses, and their tireless dedication contributed to the patient's successful transplant.

Other transplant candidates soon began contacting the organization for assistance, and it became evident that transplant candidates across the country would benefit from such an organization. The organization name was changed to Organ Transplant Fund to reflect the many different types of transplants represented.

In 1998, the board of directors voted to change the name to the National Foundation for Transplants to better convey the organization's national reach and to clearly include patients needing tissue, bone marrow or other transplants.

What began as a local endeavor has evolved into an organization benefiting thousands of organ and tissue transplant candidates and recipients. NFT currently works with more than 800 patients. In the last 10 years alone, NFT has helped patients raise more than \$26 million.

Here's to another successful 25 years!



**TRANSPLANT
EXPERIENCE**

Sharing. Informing. Inspiring.

Transplant Experience a helpful tool for patients

We know it can be overwhelming and often very frightening to deal with the challenges of transplantation, so we're always looking for resources to help patients through the process. There are many wonderful services and support groups for transplant patients, but we are especially impressed with the Transplant Experience program offered by Astellas Pharma US, Inc. This program guides, supports and motivates patients through each phase of their transplant journey.

Transplant Experience is a free program with information, tools and tips to help patients take an active role in their long-term health. Available resources include advice from health care professionals; tools to stay on track with medications, diet and exercise; personal stories from transplant patients; and much more.

Check out www.transplantexperience.com, and sign up today!

How can I help?

There are many ways to support transplant patients through the National Foundation for Transplants.

Your gift to NFT enables us to provide financial assistance, advocacy and support to transplant patients in need. When you give an undesignated gift to NFT, your donation will help NFT patients wherever the need is greatest. If you prefer, you can direct your gift to NFT's appropriate state organ/tissue fund in honor of a specified patient.

1. Give by mail

Simply enclose a check payable to NFT in an envelope.

2. Give online

Visit NFT at www.transplants.org to donate conveniently online.

3. Give by phone

Call 800-489-3863 between 8:30 a.m. to 4:30 p.m. Central Time, Monday through Friday.

4. Matching gifts

Many companies sponsor matching-gift programs and will match charitable contributions made by their employees. Some companies match volunteer hours with a donation. Call your Human Resources department for details.

5. Planned giving

You can leave a legacy by including NFT in your will or through estate planning.

6. Workplace giving

NFT welcomes gifts through workplace giving programs, including the Combined Federal Campaign and state programs. You can also designate NFT as your charity of choice in United Way campaigns.

Thank you for supporting NFT. With your help, we are raising hope and changing lives.



After a long road, Victoria received her transplant in May 2008.

Denied? Don't give up!

Many of our NFT patients receive discouraging letters from insurance companies denying coverage for transplant costs. We want to encourage you to keep appealing those letters – it worked for two patients recently!

Victoria Chavez and Rose Marburger received many denial notices from their insurance companies. The companies both stated the stem cell transplants they needed were too experimental.

After the local paper in Victoria's town ran a story about her situation, the insurance company called the following day and agreed to cover the transplant. Similarly, Rose's persistence paid off when she asked her physician to contact the insurance company and then told them she was considering approaching the media about her story.

NFT is here to serve as advocates for transplant patients. If you're having trouble getting the insurance company to help, please call us. We'll do whatever we can to help!

***NFT empowers
transplant patients
to create futures
with hope.***



National Foundation
for Transplants

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*More than 100,000 people are awaiting lifesaving transplants.
Your gift can help!*