

Getting Off the Roller Coaster

Lung recipient describes the difference her notification letter made

Editor's note: In the Nov.-Dec. Update (p. 26), you heard from kidney transplant candidate Kathe LeBeau. In her article, she told how receiving the transplant center's patient notification letter along with UNOS' patient information letter has made a difference as she awaits her transplant. She said the letters allowed her to "live with hope."

In the following article, Isabel Stenzel Byrnes describes, from the perspective of a transplant recipient, how the letters made a difference in her life.

BY ISABEL STENZEL BYRNES

My name is Isabel Stenzel Byrnes. I received a double lung transplant in 2004 in Northern California. I'm grateful to be alive and breathing, and to have the energy to serve on the OPTN/UNOS patient affairs committee.

My family and I knew we could trust the U.S. transplant system when my twin sister, who received a double lung transplant before me, was given comprehensive educational materials from her transplant center.

I was very sick with cystic fibrosis when the time came for me to be evaluated for a double lung transplant. I was on oxygen. I had limited energy. I was in and out of the hospital. I was in despair. I was terrified about both dying and getting a transplant. Yet, I was also filled with excitement for a second chance at life.

To say I was on the fence about being listed for a transplant would be an understatement.

I searched the UNOS data reports online to find the hospitals in my area with the best outcomes. After some arguments with my insurance company, I won out, and they agreed to send me to my preferred center.

The actual evaluation was a family affair: my husband and sister attended with my parents, who flew in from Los Angeles for the three-day initial clinical evaluation. We were all on pins and needles, but we were also hopeful. Just coordinating my oxygen supply for each day was an ordeal.

For the next nine months of appointments for the work-up, I presented myself as strong and physically active so I would be deemed too healthy for transplant. But my numbers told an entirely different story.

With each test, I was worried they'd find something that would disqualify me. I hesitantly made appointments, unsure if I wanted to be transplanted because I thought my life with end-stage lung disease was "manageable."

But I also felt good every time I could check off another completed test, knowing I was getting closer to getting listed—to being able to breathe again.

I was still in denial, though, and seriously conflicted. I felt I was too healthy and not ready to be transplanted—until the following winter, when my health took a nose-dive. When I was hospitalized and became critically ill, I asked to be listed.

Fortunately, I only had to do one 24-hour urine test to be eligible for the list.



When my nurse told me I was listed, I felt a huge sense of relief as the news officially affirmed that transplant was my only hope to live. My days of paralyzing indecision were over.


My husband was very relieved when we were told I was on the list. At this point, it seemed all our news had been bad news because my health was steadily declining. Knowing I was listed offered a powerful ray of hope and instigated a flurry of prayer, dreams amidst darkness and hope amidst fear.

It soon seemed, however, that I was listed too late. I fell into end-stage lung failure and said goodbye to my family. The chances of my receiving lungs were low. There were many, many other very sick people who also were on the waiting list for lungs.

I was intubated and unconscious when the patient notification letter from the transplant center arrived at home. My husband didn't even open the letter—as he was with me 24/7 at the hospital. In two weeks, donor lungs became available, and on Feb. 6, 2004, I received a transplant.

When I came home after my transplant, I finally saw the transplant center's notification letter. Holding the letter in my hand was an emotional experience—and I realized that without that letter and what it represented, I wouldn't be here today. It was my passport to life. My transplant was a miracle made manifest, thanks to my donor family.

The letter was my only tangible reminder of all the administrative and biomedical hurdles I'd gone through. It was proof that I was listed and the stars were aligned to save me.

In gratitude to all those who have played a role in saving my life, I saved the transplant center's notification letter in my scrapbook as a souvenir of my transplant miracle. 


Double-lung recipient Isabel Stenzel Byrnes is a member of the OPTN/UNOS patient affairs committee. She and her sister are the authors of *The Power of Two*, which inspired a soon-to-be released documentary of the same name (see Nov.-Dec. *Update*, p. 29).

UNOS' PATIENT INFORMATION LETTER

In her evocative story, author Isabel Stenzel Byrnes describes hearing she was on the transplant waiting list and then the importance of later receiving the transplant center's official notification letter.

Policy requires that transplant centers include a patient information letter from UNOS along with their own notification letter. The OPTN/UNOS patient affairs committee has recently redesigned UNOS' patient information letter, which now resembles a one-page flier with key contact information.

All transplant centers are required to transition to the new UNOS patient information letter by **April 24**. The patient affairs committee and UNOS' department of evaluation and quality will present a webinar on use of the UNOS patient information letter in waitlist notification on Wed., **March 9**, at 1:30 p.m. ET.

 The UNOS patient information letter is available at <http://optn.transplant.hrsa.gov> (resources > professional resources > patient information letter). To register for the webinar, visit <https://unos.peachnewmedia.com/store/seminar/seminar.php?seminar=6929>. After you've registered, you will receive an e-mail and invitation with details. Questions? Send an e-mail to patientnotify@unos.org.


CTSE NAMES RESEARCH TEAM


Eleven experts, representing diverse fields—system dynamics, epidemiology, biostatistics, quantitative geography and behavioral health—have been named as investigators in a national study to determine the future number and trends of potential deceased organ donors in the United States.

The study is the first major initiative of the Center for Transplant System Excellence (CTSE). UNOS recently formed the center to leverage the expertise and capabilities of UNOS staff in collaboration with academic and clinical researchers with an interest in advancing the field of transplantation. The study is supported by \$1.7 million in funds from the Health Resources and Services Administration, Department of Health and Human Services added to UNOS' existing OPTN contract.

Karl McCleary, Ph.D., M.P.H., is the study's principal investigator. He is the CTSE's scientific director and affiliate assistant professor in social and behavioral health at Virginia Commonwealth University's School of Medicine in Richmond.

Gary Hirsch, S.M., is the co-principal investigator. He is the creator of Learning Environments in Wayland, Mass., and an adjunct faculty member with the Division of Health Science and Technology, Harvard University, and the Massachusetts Institute of Technology.

Co-investigators include the following: L. Ebony Boulware, M.D., M.P.H., associate professor of medicine and epidemiology, the Welch Center for Prevention, Epidemiology and Clinical Research, Bloomberg School of Public Health, Johns Hopkins Medical Institutions; Leah B. Edwards, Ph.D., assistant director of research, UNOS; Gary King, Ph.D., M.A., professor and director, Institute for Quantitative Social Science, Harvard University; Kevin A. Myer, M.S.H.A., business director, CTSE; Michael Reibel, Ph.D., professor, department of geography and anthropology, California State Polytechnic University, Pomona; John D. Rosendale, M.S., senior performance analyst, UNOS; Khalid Saeed, Ph.D., M.Eng., professor, economics and system dynamics, Worcester Polytechnic Institute, Worcester, Mass.; Laura Siminoff, Ph.D., M.A., professor and chair, cancer prevention and control, Virginia Commonwealth University, Richmond; Samuel Soret, Ph.D., M.P.H., associate professor and chair, department of environmental occupational health, Loma Linda University School of Public Health, Loma Linda, Calif. 

 For more information, visit the Center for Transplant System Excellence website at transplantexcellence.org.