

The **AJT** Report

News and issues that affect organ and tissue transplantation

Transplantation at the Grassroots Level

Groups provide support, education and advocacy to transplant recipients, donors and families

After a liver transplant at the age of 24, Nelson Freytes found himself on unfamiliar ground.

“I was a healthy person who was suddenly thrust into a world of medication talk and alien technical terminology,” says Freytes, a marketing specialist who was extremely uncomfortable with and lost in the medical environment. When he discovered the Transplant Games and met other transplant recipients, he became more comfortable with his shift in lifestyle, and realized that he would like to pass on this type of support to other transplant patients and families. “It balanced things out for me, and I wanted to harness that side of it,” he said.

In 2007, Freytes invited writers from transplant blogs and information sites to participate in a new online community for transplant patients that he had developed—Transplant Café (www.transplantcafe.com). Since its debut, the patient website and a partner Facebook group have attracted approximately 6,000 members. “People latched onto the site,” he says. “They found support for each other and were able to express themselves.”

Transplant Café followed in the footsteps of another website, Transplant Buddies (www.transplantbuddies.com), which was launched in 1999. The site provides information about the transplant process, resources covering drugs and side effects, and daily discussions about living life as a transplant patient. In recent years, the site founders developed an updated companion site, Transplant Friends (www.transplantfriends.com), and put the two together on Facebook, calling the group Transplant Buddies and Friends (facebook.com/TransplantBuddiesFriends). “We have many thousands of members within the two websites,” says site host Risé Pine.

These grassroots transplant organizations and others like them have grown in number and size over the past decade. These groups are born out of a growing need for transplantation advocacy and support—for both patients and their families.

Additional Support

Since 1987, the nonprofit group Transplant Recipients International Organization (TRIO) (www.trioweb.org) has aimed



The Philadelphia chapter of TRIO has published a book for children who have a family member who has had a transplant. Aimed at 5- to 8-year-olds, the pictures and text were created by children of transplant families. The book is available free of charge www.trioweb.org.

to improve the quality of life for transplant candidates, recipients, their families, and the families of organ and tissue donors. Through a headquarters and network of 16 U.S. chapters and one in Japan, TRIO has approximately 1,200 members.

TRIO president James Gleason, a 20-year heart-transplant recipient, says the organization offers Internet newsletters, scholarships, a transplant library with 65 programs that chapters can borrow for presentations and a place where anyone can donate airline miles to a transplant candidate/recipient. The national headquarters and chapters participate in a public policy committee to advocate for national and local legislation. Additionally, each chapter offers special activities.

In addition to TRIO's help in providing airline miles to transplant families, the American Organ Transplant Association (AOTA; www.aotaonline.org/transportation.html) has partnered with Greyhound Corporation for bus travel

within the contiguous United States for transplant recipients and caregivers. Additional transportation resources can be investigated at Miracle Flights for Kids (www.miracleflights.org), Air Care Alliance (www.aircareall.org) and Angel Flight South Central (www.angelflightsc.org).

KEY POINTS

- Grassroots organizations involved in transplantation have grown in number and size over the past decade.
- These groups are born out of a growing need for transplantation advocacy and support—for both patients and their families.

In October 2014, the *Atlantic* magazine told the story of Sridhar Tayur, a professor and software entrepreneur, who decided “to help patients find out where in the country they could go to get a liver or kidney the fastest, and then promised a private jet to fly them there at a few hours’ notice when the organ becomes available.”¹ Tayur told “The *AJT* Report” that 300 individuals have signed up for his offer. “Advice and signing up are free →

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through the patient advisory service," he says. "Actual travel is based on market prices, about \$8,000 per flying hour." Tayur is currently trying to obtain insurance coverage for the service.

Local housing has been made available for transplant families, such as Transplant House in Seattle, Wash.; Transplant House of Cleveland; The House in Middleton, Wis.; and Gift of Life Family House in Philadelphia.

Grassroots fundraising often helps individuals in need of a transplant. In addition to websites such as Kickstarter, Indiegogo and Crowdfunder, where individuals can ask for donations toward their transplant, organizations such as the National Foundation for Transplants (NFT; www.transplants.org) and HelpHopeLive (www.helphopelive.org) provide fundraising advice or directly assist requestors. For example, at an NFT-arranged fundraiser that took place last November in Jacksonville, Fla., a portion of the proceeds from a local restaurant went to a local transplant patient.

Caregivers

Although numerous resources are available to caregivers, none are specific to transplant families, say Renee Ambrosio and LeeAnn Fitzgerald, cofounders of the Facebook group Transplant Caregivers: Partners for Life ([facebook.com/groups/PartnersForLife](https://www.facebook.com/groups/PartnersForLife)), which now has more than 600 members throughout the world.

On other support sites, Fitzgerald says postings can be perceived as negative, drawing criticism from viewers. "You'll get a lot of people saying, 'How could you feel this way? How can you take your gift for granted?'" she says. "We wanted a place where people could share their feelings without fear of judgment."

Ambrosio adds that "many transplant patients react negatively and, at times, defensively when a caregiver posts their feelings of fear and frustration. Their interpretation of a caregiver's post may be misconstrued." Therefore, the Transplant Caregivers site is a closed group accessed only by member caregivers. Fitzgerald and Ambrosio vet requests from transplant-specific caregivers, who can then openly discuss their fears, concerns and issues.

Toward the Future

The Transplant Café recently announced that the website had

Posttransplant Cancer Information Site

Last spring, James Gleason, president of Transplant Recipients International Organization (TRIO), received a phone call from a chapter representative informing him that an active member of the patient support group had died of cancer—yet another loss to posttransplant cancer. Gleason was unsure what their group could do.

He eventually decided that TRIO could offer a comprehensive post-transplant cancer website for members and the public. The five-year project is scheduled for completion in 2019. The first pages should be available

by March this year, accessible through the TRIO website, www.trioweb.org. When the site is complete, it will include the different types of cancer that are specific to each transplanted organ type. There will be information on risk, as well as a cancer timeline that includes prevention, symptoms, diagnosis and treatment advice.

"We're starting to record three- to five-minute interviews with doctors about specific organs," Gleason says. "We'll eventually have a 30-minute to one-hour presentation that would be available as public information and for use in presentations."

partnered with Edison Nation Medical, a company that provides inventors with a pathway to submit a transplant-related invention or idea for potential commercialization. If the idea is successful, the company splits licensing royalties 50/50 with the inventor.

"We are hosting a yearlong search to uncover transplantation ideas," says Edison Nation Medical representative Julie Wheelan. "Every idea submitted to the company is vetted through an extensive eight-stage evaluation process. We then invest 100% of any resources necessary to successfully commercialize ideas that our evaluation team believe are most promising."

A "New Regimen"

Before Fitzgerald's husband underwent a heart transplant in 2011, she remembers watching him deteriorate, fearing that he would die. After the transplant saved his life, "there were so many feelings to reconcile, such as someone having to die for my husband to live," she says.

Prior to a transplant, caregivers are in a certain mode of caregiving, she says. There are certain regimens, medications and things the patient can and can't do. After the transplant takes place, she says, "All of a sudden, it's a whole new regimen dropped on you—forget everything you've done before and learn to live with a whole new set of things."

These organizations, focused on offering tools, information and a support community, aim to help patients, families and caregivers cope with the challenges, and to help give them a voice.

Reference

1. Lamas DJ. A private jet is waiting to take you to your kidney transplant. <http://www.theatlantic.com/health/archive/2014/10/the-businessman-disrupting-organ-transplantation/381843>. Updated October 29, 2014. Accessed December 8, 2014.

Minimal Risk for Living Kidney Donors Who Become Pregnant

A recent study by Canadian and U.S. researchers found that living kidney donors who later became pregnant were more likely to be diagnosed with gestational hypertension or preeclampsia than nondonors.¹ There were no other differences between the donors and nondonors regarding maternal and fetal outcomes.

The retrospective cohort study matched 85 living donors with 510 nondonors between 1992 and 2009. Donors had approximately a one in 10

chance of developing gestational hypertension or preeclampsia in a pregnancy after donation compared with the expected chance in nondonors of one in 20.

"Living kidney donation is an important treatment option for kidney failure that clearly benefits many families and society," says the article's first author, Amit Garg, MD, director of Living Kidney Donation at London Health Sciences Centre in Ontario, Canada. "We are reassured that most

women we studied had uncomplicated pregnancies after kidney donation. These findings can be shared with potential donors and recipients as part of the informed consent process to proceed with transplantation," he says. [AJT](#)

Reference

1. Garg AX, Nevis IF, McArthur E, Sontrop JM, Koval JJ, Lam NN, et al. Gestational hypertension and preeclampsia in living kidney donors [published November 14, 2014 online ahead of print]. *New Engl J Med*. doi: 10.1056/NEJMoa1408932.