

## **How TRIO Serves the Transplant Community**

TRIO's activity is critical to advancing the interests of transplant recipients, donors, those who are desperately waiting for a transplant, and concerned family and friends. By fulfilling its mission of awareness, support, education and advocacy, TRIO supports a number of important initiatives in its efforts to serve the transplant community.

### **Washington and other governmental advocacy**

TRIO national has played a very active role in shaping national policies and state legislation on behalf of transplant recipients. Our Board members serve on the UNOS Advisory Committee, participate in meetings of the Advisory Committee on Organ Transplantation for the Secretary of Health and Human Services, Washington's Transplant Roundtable, and.....

TRIO also advocates for favorable policies to promote living donation, pilot studies on the benefits of providing incentives to promote organ donation, issues surrounding long-term care, and organ allocation policies that maximize benefits to all potential transplant recipients. In September 2007, Elizabeth Rubin, Past-President of TRIO, represented transplant recipients and patient advocacy groups in her testimony before the U.S. House of Representatives Committee on Oversight and Government Reform, stating in part: "What has been done to encourage people to donate has been quite successful; . . . however, none of these efforts have done enough: the number of organ donors is not keeping pace with the number of patients on the waiting list."

The higher the number of members of TRIO, the more powerful the voice of transplant recipients will be in the government.

### **Media Advocacy**

If you watch television regularly, you have probably noticed episodes on shows like *Law & Order* and *Grey's Anatomy* that misrepresent organ donation by playing on common myths.

Research shows that watching these shows has adverse effects on people's willingness to sign up to become organ donors. TRIO is playing an active role in trying to stop these misrepresentations of organ donation. Board members actively meet with Hollywood writers and producers to offer information, support, and public pressure to motivate them to develop more accurate storylines. A member of the TRIO Board of Directors serves on the Advisory Board of Donate Life Hollywood.

Our active involvement with media advocacy allows us to provide quick alerts to our members about recently aired shows with detailed information about the myths being depicted, transcript excerpts, and even video clips (via email) so TRIO members can write to the writers and producers of these shows using the

detailed contact information we provide. These efforts have met with some impressive success in the time that these coordinated efforts have begun. In this way, we are developing a more donation-friendly public environment that will be more receptive to organ donation promotion campaigns.

The more TRIO members we have, the more likely Hollywood movie studios as well as television network writers and producers will pay attention to the concerns of transplant recipients. We seek to present ourselves as a powerful contingent of concerned consumers who demand responsible media representations of organ donation.

### **Educational Symposium**

TRIO is very excited to have the opportunity to work with ITNS in co-hosting the ITNS/TRIO Symposium to be held in St. Louis, MO, on September 25-27, 2008. The Symposium will bring together more than 450 transplant nurses (Certified Transplant Care Coordinators), more than 200 transplant recipients, donors and their families, renowned transplant physicians and researchers through keynote sessions, educational sessions, workshops and exhibits.

### **Liaisons to the Transplant Community**

TRIO members provide representation to several national organizations that impact transplant recipients, people on transplant waiting lists, and their families. A full list of organizations and TRIO liaisons can be found on [www.trioweb.org](http://www.trioweb.org), among them:

- Donate Life America.
- Washington Transplant Roundtable.
- At-Risk (Skin Cancer).
- Other nationally recognized organizations, such as: UNOS, NKF, AHA, ADA, among others.

As a result, the voice of TRIO can be heard in all arenas that affect transplant recipients. Without a national organization, we lack central organizing power that allows our voices to be heard.

### **TRIO Website**

The TRIO website offers valuable resources for transplant recipients, those waiting for transplants, their friends and family, and the concerned public.

#### *Important information and answers to questions*

Through its various information resources, TRIO attempts to respond to questions and matters of interest. We do not have a staff of experts. Instead, TRIO relies on volunteer advisors, its Board of Directors and its chapter contacts to answer questions and provide information. The supportive network of TRIO members providing important information about the pre- and post-transplant issues and processes is an excellent benefit provided by TRIO.

#### *Bulletin Board*

Did you know that you can share with others, by topic, or just chat in general, on TRIO's website Bulletin Board? You can register your comments and visit later to find if anyone has responded. You do not have to be a member of TRIO to use the sharing element of the Bulletin Board. Just go to [www.trioweb.org](http://www.trioweb.org) and click on the link to the Bulletin Board. There you will find varying inputs and opinions and you may share your thoughts, questions and interests. (You do need to register to share your input.)

#### *Link updates*

TRIO seeks to provide the transplant community with useable and productive links to excellent resources for transplant recipients from its website. In its constant effort to relay correct information, TRIO website management would like your input. If you find a link that is out of date or not responsive, please let TRIO know so that we may better serve the public on transplant related issues. Contact [sleach@trioweb.org](mailto:sleach@trioweb.org) with updates, corrections, additions or suggestions for beneficial links.

#### **Lifelines Newsletter**

Publish your opinions and articles TRIO's newsletter, *Lifelines*. The newsletter accepts articles for consideration if they are of interest in the transplant community. Send a letter of inquiry (not the article) to [sleach@trioweb.org](mailto:sleach@trioweb.org). You will be contacted by a member of the Newsletter Subcommittee relative to the acceptability for publication of your submission. Your "OPINION PAPER" can also be published on TRIO's website.

Previous articles in *Lifelines* have covered topics such as the importance of physical activity to transplant recipients' long-term health, the effect of the media on the public's willingness to donate and the many successes associated with TRIO chapters' activities.

Future articles in *Lifelines* will address topics such as managing medication, navigating insurance/Medicare/Medicaid, legislation relevant to transplant recipients, and personal articles from our scholarship recipients.

The *Lifelines* newsletter is an exclusive benefit for TRIO members.

#### **TRIO scholarships**

With over seventy \$1,000 scholarships awarded over the past 12 years, TRIO continues to offer academic grants to deserving students who are transplant candidates, recipients, donors or their family members. The deadline for 2008 applications is June 30, 2008. An application can be downloaded (click on RESOURCES at [www.trioweb.org](http://www.trioweb.org)). These scholarships are generously funded by several TRIO chapters, the Board of Directors, individuals and interested organizations. Please join us by making your own generous contribution to this TRIO scholarship program.

## **TRIO Chapters and membership**

One of TRIO's goals is to expand its outreach to the transplant community through increasing membership in its Chapters and its Members-at-Large community. TRIO strongly believes in the value of local affiliation and supports the activities of its local chapters. We urge you to join with your fellow recipients, donors, and their families in the many activities conducted by local chapters. In addition, TRIO seeks to serve long-term recipients who may not be receiving helpful support information from other support groups that focus on more recent transplant issues.

## **Developing chapters or support groups**

If you are interested in enjoying the support that a local chapter of TRIO can provide, TRIO National can assist you in starting a support group or a TRIO chapter. To inquire, contact [info@trioweb.org](mailto:info@trioweb.org). By inquiring, you are not committing to start a chapter or support group. Perhaps you would be willing to serve as a contact point in your geographical area to reach out to other transplant recipients, donors or their families?

## **How else are membership dues spent?**

- TRIO national must pay for an annual audit as a condition of its non-profit status.
- TRIO pays an hourly rate to our managing director who performs a variety of important tasks, including website content management, answering telephone inquiries, coordinating Board meetings, responding to individual and chapter member needs, planning the annual meeting for TRIO members, newsletter editing, production and printing, 800# telephone responses, 'info@trioweb.org' email responses, support of all officers, committees and chapters, maintenance of TRIO's national non-profit status and financial record keeping (accounts payable, audit support). The Managing Services Director manages the affairs of TRIO and maintains the functionality of a national office.
- Small scholarships for transplant recipients and their family members.
- TRIO pays to print brochures that are distributed to transplant recipients and other potential new members.
- TRIO incurs conference call costs when TRIO Board members do not meet in person and provides conferencing facilities for chapter presidents' meetings.

## **The TRIO Board of Directors**

Current and potential new TRIO members should note that members of TRIO's Board of Directors support TRIO activities by donating their time and energy as well as considerable expenses associated with attending TRIO Board meetings (travel, hotel, meals).

## **Initiatives we would like to support in the future:**

- Development and distribution of PSA promoting organ donation featuring key celebrities
- Education through future symposiums and conferences
- Training and educational workshops for Chapter officers.

### **How Can You Help Others?**

#### *Provide a life-saving airline flight*

Through TRIO's partnership with United Airlines, TRIO/UAL offers frequent flyer mileage tickets to recipients and donors who might not otherwise be financially able to transport themselves to transplant centers for life-saving procedures. Donate your United Airlines frequent flyer miles to TRIO's life-saving ticket program. Call United Airlines at 1-800-421-4655. These tickets have various restrictions. Information relative to the TRIO/UAL Charity Miles Program can be accessed on [www.trioweb.org](http://www.trioweb.org), under the topic "Resources." TRIO is deeply appreciative to United Airlines for their continued support of this program. Remember: when possible, FLY UNITED AIRLINES! Thank you for helping others!

#### *Lend-a-Helping-Ear*

You may be of service to others if you are willing to participate as a 'responder' to questions. Please contact [sleach@trioweb.org](mailto:sleach@trioweb.org) to offer your services. Or, you can fill in and email the form from TRIO's website (under Lend-a-Helping Ear). No expertise is required—just a willingness to try to assist others in seeking answers to their questions.