



Transplant Recipients International Organization, Inc.

2100 M St., NW, #170-353; Washington, DC 20037-1233

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Annual Report

Year of 2013

President's Letter

Meeting TRIO's Goals in 2013
Leads to:

Expanded Services and Outreach Activities in 2014

TRIO 2014 Board of Directors



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To the Transplant Community:

As we enter our 27th year of service to the transplant community, TRIO is proud of what we have accomplished in the past year, through fulfillment of our missions:

- *Awareness*: Promoting public awareness of the importance of organ and tissue donation and transplantation;
- *Education*: Educating members of the transplant community with current information on developments in transplantation, medication, social and financial issues;
- *Support*: Providing emotional support to transplant candidates, recipients, their families and donor family members;
- *Advocacy*: Advocating the concerns and needs of members for national and local legislative efforts to benefit transplant candidates, recipients, their families and donor family members.

We have demonstrated our ability to manage growth and generate action to further awareness of the need for organ donation, provide educational and emotional support to the transplant candidate, recipient, donor and donor family members and to serve as an advocate for the transplant recipient and donor at the local community, state and national levels.

TRIO's mission calls for us to do even more for the transplant community! In our continuing efforts to grow and better serve the transplant community, TRIO is pleased to have a strategic plan in place to guide us in that growth. The following annual report describes growth-oriented accomplishments and progress in 2013 and shares our movement forward into 2014 with continuation of current programs and development of new programs. As our membership grows and with new chapters forming, we invite members, chapters and supporters to become fully engaged in our work at the local and national levels.

Together, we are making a difference in this world.

Sincerely,

James Gleason
President, TRIO Board of Directors
Heart Transplant Recipient, Oct 19, 1994



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Meeting TRIO's Goals in 2013 Leads to Expanded Services in 2014

Goal: Expand Mission-Oriented Service Programs

In addition to its on-going service outreach programs discussed on pages 5-8, TRIO continues to expand its mission-oriented service projects to enhance and support the transplant community through activities such as a campaign to enlist primary care physicians in organ donation awareness, the Transplant Presentation Library, a monthly news email, a Leadership Summit to offer training to chapters and generate leadership continuity, and through contact points and chapter development.

Primary Care Physician Awareness Campaign

This nationwide TRIO-led campaign seeks to enlist local primary care physicians in raising awareness of organ donation options for their patients. This campaign is in response to a recent study indicating that only 6% of primary care physicians are talking to their patients about signing up to be organ donors, while 70% agree that it is within their domain to do so and 95% say they are in favor of organ donation. This grass roots effort, initiated in 2011, is enlisting TRIO members to make a difference in organ donation in their own local communities. With Pfizer grant support, the Primary Care Physician program was formally launched for nationwide implementation at the 2011 Leadership Summit, held in Washington, DC.

TRIO Transplant Presentation Library Grows to 60 Programs!

In 2009 TRIO launched the first monthly presentation library DVD recordings as an aid to both chapters and the transplant patient community, providing professional informational presentations available for a much wider audience. Now going on five years later, that library is still growing monthly with sixty topics currently available. The TRIO Transplant Presentation Library program is an educational resource, offering each chapter a monthly DVD containing an hour-long presentation from recent meetings where noted transplant professionals have shared on some of the topics of interest to our transplant community.

The purpose of this program is to provide affordable and expert presentations to a wide range of our nation-wide membership, both as event audience presentations and as library loan materials for the individual who may not be able to attend the audience event showing of a particular program. For those outside the local geography of a TRIO chapter (known as Members-at-Large), individual requests for programs make these DVD's available to all TRIO members.

The materials are delivered to local chapters bi-monthly. TRIO maintains a supply of each DVD for replacement purposes at no charge to chapters. Should a chapter wish to record

and submit a program for inclusion, they are provided User Guidelines, Recording Guidelines, and Presenter Release Forms.

Selected DVDs are also delivered (at no charge) in response to requests from Transplant Centers and Organ Procurement Organizations.

Mentoring Program for Member and Chapter Growth: *TRIO Leadership/Educational Summits.*

In 2010 TRIO held its first Leadership/Educational Summit in Philadelphia, PA, at the Gift of Life Donor Program (OPO) offices. Based on the success of (and feed-back from) the 2010 Leadership Summit, future annual summits were developed to provide more pointed leadership training to TRIO's current and potential chapter leaders and officers and to raise their personal level of commitment and leadership effectiveness. Video recordings of all Leadership Summit presentations have been made available on the TRIO web site to reach an even wider audience than those who were able to attend in person. To assist developing chapters, TRIO will develop and involve currently established chapters in a mentoring program to offer advice and assistance to developing chapters. In the past, through program grants from pharmaceutical companies, TRIO offered chapter representatives substantial scholarship funding to off-set the cost of attending the summit.

Plans are currently underway to hold TRIO's 2014 Leadership/Educational Summit in Los Angeles on September 19-20.

Goal: Plan for the Future

TRIO's Strategic Plan continues to guide the organization 'looking forward.' Specifically, this action plan addresses three key functional goals that will lead the organization in achieving growth and result in these key focused categories. The three priorities, carefully aligned with the TRIO mission and vision are:

- Increase Capital Resources (Human and Financial)
 - o Grow Membership Base (Human Capital)
 - o Develop and maintain a strong financial position for TRIO
- Enrich Internal Communications
- Inculcate "One TRIO" Culture

Goal: Pursue a Program-Oriented Funding Approach

One of TRIO's on-going objectives for 2014 is to continue to develop a plan to strengthen its financial base. With the low membership dues and recognizing the financial challenges and constraints of most transplant recipients, along with the current impact on donations resulting from the national financial situation, TRIO is actively pursuing a more balanced funding approach to fund its current and future operations and projects.

Goal: Maintain Full Board of Directors

TRIO is most fortunate to have a dedicated Board of Directors who serve without compensation. All Board of Director seats are currently filled and these current members have agreed to continue serving on TRIO's Board in 2014. Should a Board vacancy occur, TRIO's Nominating Committee continues to seek out and review Director candidates who will contribute a broadened professional acumen and personal dedication to transplantation.

Goal: Increase Membership Base

In 2014, TRIO seeks to increase its membership base through chartering of new chapters. Two new TRIO chapters were added in 2013: TRIO Maryland (Baltimore) and TRIO Pacific Northwest (Seattle). Continued expansion of the membership in 2014 is a high priority with TRIO's Board and Managing Services Director.

Another avenue for attracting members is the development of a "Chapter Without Borders." This virtual chapter gives focus to the Member-at-Large group. With proper support, this group can be offered interactive organizational structure through audio conference meetings, thus promoting closer contact and developing expanded ability to accomplish TRIO's mission.

Goal: Provide Support & Communication Avenues to Transplanted Youth

In seeking to engage the younger transplant recipients, TRIO has established a "Youth Circle" to provide information and guidance through social media and a "Youth Circle" newsletter column addressing the needs of this newly identified transplant population. TRIO's website offers an identifiable section dedicated to transplant youth, their accomplishments, concerns and involvement in the community. When appropriate funding is available, TRIO plans to provide a thirteen week web-based "Youth Employment Workshop" to train and assist transplanted youth in their search for employment.

Goal: Develop New Communication Resources for Members and Community

Previously, TRIO initiated new paths of communication with specific segments of its membership. Through use of Constant Contact, TRIO began producing regular electronic newsletters to its Board of Directors, Chapter Presidents and membership in general.

In 2014, TRIO seeks to add another regular e-blast service to communicate and support its growing number of members at large as a Virtual Chapter, thus rounding out its current communications toolbox of an online *Lifelines* newsletter, e-mail based e-news and internet website.

TRIO continues to support and expand its on-going outreach services programs

- **Donor Awareness Events:** Nationwide, TRIO chapters hold organ and tissue donation awareness events throughout the year. In addition to the numerous chapter-supported awareness activities, all TRIO chapters are involved in annual April Donate Life Month activities. During April, many TRIO chapter members visit churches, temples and mosques across the United States to help promote organ and tissue donation. TRIO chapters nationwide celebrate National Donor Sabbath during the second weekend of November with similar donor awareness events in their local Houses of Worship. As an example, TRIO Long Island Chapter recognizes donor families in an annual TRIO rose garden ceremony that attracts a large crowd and is well publicized. In yet another amazing annual event, TRIO Manhattan hosts a huge donor recognition ceremony, filling the large St. Patrick's Cathedral each Spring with recipients honoring donor families in this very special ceremony.
- **Airline Flights for Transplant-related Procedures:** TRIO is pleased to be one of only 30 non-profit organizations in the United States selected by United Airlines to participate

in the Charity Miles Program. Since 2001, TRIO National has partnered with United Airlines to arrange no-cost flights for any patient, with financial need, traveling to a transplant center for pre-transplant evaluation and post-transplant follow-up. Since its inception, the TRIO/UAL partnership has provided hundreds of round-trip tickets to the transplant community. This program is supported through frequent flyer mileage donations from TRIO members and friends.

- **Personal Response to Public Inquiry:** TRIO national maintains a highly publicized toll free number (1-800-TRIO-386) to receive calls from anyone interested in obtaining information about organ donor awareness, transplantation in general, or who has specific concerns or questions. Specific concerns or questions requiring expertise are referred to one of our volunteer peer counselors.
- **Website:** TRIO maintains a highly visible and well-promoted web presence (www.trioweb.org). On its website, TRIO provides the transplant community with news, information, chapter activity reports, ideas and contact information, and support group information through geographical contact points. TRIO's website offers access to a Bulletin Board, where anyone can visit (at no charge) to ask questions and respond to other entries. The web site also offers reviews and recommendations of books and movies relating to transplantation and approximately regularly reviewed 800 organized transplant related links. Through this website we invite any online reader to contact info@trioweb.org with questions or concerns about transplantation. These 'info@' emails are answered by our national office or are forwarded to one of our volunteer peer counselors. In 2013, TRIO's website was re-designed and continues pertinent and timely updates, including such indexed areas as: "Prescription News of Transplant Interest," "Patient News," "Legislative Actions" (including Transplant Roundtable recent actions), and "Transplantation in the News."
- **Newsletter – Lifelines:** In 2014, as part of its efforts to control costs, TRIO moved from a hard copy postal mailing to publishing a quarterly electronic newsletter, sharing transplant-related information with its members, friends, transplant centers and Organ Procurement Organizations.
- **Organ Procurement Organization (OPO) Partnerships:** All TRIO chapters have established supportive and interactive relationships with the organ procurement organizations in their geographic area. Chapter members volunteer as Donate Life Ambassadors. As Donate Life Ambassadors, many TRIO members assist in speaking at and holding organ donor awareness events at high schools, colleges, transplant centers, etc.
- **Legislative Information:** TRIO national maintains active representation on the Washington, DC-based Transplant Roundtable. The roundtable is comprised of the major non-profit organizations in the United States that have an interest in transplantation (i.e., National Kidney Foundation, American Liver Foundation, American Heart Association, American Diabetic Association, American Association of Kidney Patients and the Renal Support Network). The Roundtable works with members of Congress to promote new funding for transplant recipients and for those on the transplant waiting list. As just one example, the Roundtable works to assist promoting a bill that will extend coverage of immunosuppressant medications beyond the present three-year limit for renal transplant

recipients. Similarly, TRIO works to provide education and encourages members submission of public comments directly to the sponsoring agency for such critical issues as was done with the new UNOS kidney allocation policy and most recently with the protective drug class issue with CMS. Individual chapters also work within their own states to provide testimony and support for state legislative issues affecting organ donation and transplantation.

- **Donate Life Hollywood:** TRIO national is a founding member of Donate Life Hollywood, an organization dedicated to countering the adverse effect of misinformation by the media in TV story lines about organ donation. Donate Life Hollywood is a consortium of OPOs across the United States, major transplant centers and many non-profit organizations that have come together to respond to the shows' producers and writers when the public sees inaccurate and misleading story lines about transplantation.
- **Donate Life America:** TRIO is a Partner in the Donate Life America organization's efforts to promote organ donor awareness, a partnership that includes all 58 organ procurement organizations across the country.
- **Pasadena Rose Parade:** TRIO national and its chapters continue to be supporters of the annual Pasadena Rose Parade Donate Life Float entry. The TRIO California Chapters (Ventura County/West Valley and San Francisco Bay) provide volunteers to decorate the float for the Rose Parade. The Donate Life America float focuses on raising awareness to the shortage of organ donations.
- **Chapter Meetings:** TRIO chapters hold monthly or bi-monthly support meetings with guest speakers from the medical community to provide members with up-to-date information and to discuss changes within the transplant community. TRIO chapters have numerous medical advisors available to answer questions arising at chapter meetings. TRIO chapters have been asked to designate a Public Policy "chapter champion" to be responsible for communicating each chapter's public policy input to the TRIO national Public Policy Committee.
- **TRIO Scholarships:** Each year TRIO awards several \$1,000 educational scholarship grants to transplant recipients, donors or their immediate family members. These grants, funded by contributions from individuals, TRIO chapters and other organizations, are for higher education purposes. TRIO's scholarship web page also serves as a clearinghouse by promoting other scholarship opportunities. In 2013, six \$1,000 scholarships were awarded.
- **Motor Vehicle On-Line Registries:** Chapter members across the United States continue to work to promote an online DMV registry in their states. Most states have now activated this system. TRIO volunteers man information tables at motor vehicle offices and provide personal testimony to state motor vehicle employees who interface with drivers responding to the opportunity to register as organ donors at such offices.
- **UNOS Support:** TRIO, as a national organization, and some individual TRIO members continue as official voting members of UNOS (the United Network of Organ Sharing) and the OPTN. Individual chapters and at-large TRIO members across the country support the work of UNOS with their volunteer participation on its many committees that

oversee the process of organ allocation under contract to the government. Members also serve on the UNOS national elected board as well as on special consultant sub-groups, representing the patient and recipient voice in this important work.

- **US & World Transplant Games Support:** TRIO chapters support local transplant games teams along with many other TRIO members regularly participating in games' competitions, showing the world that transplantation works and thus encouraging registration as organ donors.

TRIO is proud of what we have accomplished in recent years, returning to a solid financial base over multiple years primarily with volunteer labor from TRIO chapters, members and the Board of Directors. We have demonstrated our ability to manage growth and generate action to further awareness of the need for organ donation, provide educational and emotional support to the transplant candidate, recipient and donor family members and to serve as an advocate at the community and national level.

Our mission calls for us to do more for the transplant community! With the approaches outlined above, we present expanded agendas through which TRIO and its chapters can better serve the transplant community and further the causes of *Donor Awareness, Support, Education* and *Advocacy*, thereby increasing organ donation and organ transplant.

Submitted by
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See 2014 Board of Directors, below.

TRIO 2014 Board of Directors

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