“Your Voice of the Transplant Community”

TRIO Annual Report 2019
2019 was a year of substantial transition and progress for TRIO as the organization displayed flexibility and innovation as it continued its work to meet the goals of its mission:

- **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.

TRIO ended 2019 improving its already solid financial condition by employing new technologies which allowed additional reductions in costs without affecting activities or organizational resources.

2019 was a year marked by change in several key areas:

- **Staff Retirement and Transition** – After 17 years of outstanding service to TRIO, Sylvia Leach, TRIO’s Managing Director, retired with the gratitude of the entire national organization and its chapters. Ms. Leach was replaced in the chief staff role for TRIO by Gary Green, who was TRIO’s Vice President. The office was relocated from Virginia to Florida. During this transition period, all programs of TRIO continued to be available and ably managed by former and new staff.

- **Virtual Tools**. Adapting to the new opportunities of a changing world, TRIO in 2019 adopted Zoom as its technology platform of choice for conducting its committee and Board meetings. Also, the national headquarters has gone “virtual” to a large extent, with telephone communications now being routed dependent on day and time of day. In addition, a new online giving platform, Qgiv, has been employed to provide for an easier and seamless donation experience.

- **New Organizational Processes**. In 2019, the Board of Directors reviewed and adopted revised Bylaws, which will serve as a blueprint for streamlining how the organization operates. Terms of service for Board members have been established and the committee structure was updated to better reflect how TRIO now operates.

- **Team USA/World Transplant Games**. In 2019, TRIO became the new home of Team USA, the team of American transplant athletes which competes in the events and activities of the World Transplant Games Federation. Over 200
Americans traveled to Newcastle, United Kingdom, for the 2019 World Transplant Games. Team USA athletes returned with scores of medals, outstanding athletic performances, and wonderful memories of their fellow transplant athletes from around the world.

- **Communications** – TRIO continues to increase its social media presence with Facebook, monthly E-News distribution and its well-recognized, resource-rich, and timely news content web site. In collaboration with many other related advocacy organizations, TRIO’s public policy team has engaged political leaders regarding important transplant issues and partnered at the national stakeholder table in supporting public concern and legislative actions.

- **Cancer post-transplant** – TRIO continued to enhance its educational web site addressing the higher risk of cancer in transplant patients. The web site’s Learn, Look, Live and Links sections offers patient testimonial and medical staff videos in addressing this leading cause of death in transplant recipients with its message of early detection and prompt effective treatment.

- **Strategic Plan Review.** The Board of Directors underwent a major review of TRIO’s strategic plan. The revised plan will allow TRIO to focus more directly on the issues and programs that the Board has prioritized for the organization in the coming years.

TRIO continues to move forward in advocating for transplant recipients in all aspects of their lives. Our mission and the need remain strong…..

……Together, we are a reckoning force, now 33 years, continuing to make a difference in this world of organ donation and transplantation with your engagement and support.

Sincerely,

Jim Gleason

TRIO President
TRIO Board of Directors

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About TRIO

TRIO (Transplant Recipients International Organization, Inc.) is an independent, not-for-profit, international organization committed to improving the quality of life of transplant candidates, recipients, their families and the families of organ and tissue donors.

Through the TRIO Headquarters and a wide network of local chapters, TRIO serves its members in the areas of: Awareness, Support, Education, and Advocacy. A TRIO web site is filled with information about these areas and our many programs, including local chapter contact information, at http://TRIOweb.org. E-mail us at info@trioweb.org or call 1-813-800-TRIO.

Mission

TRIO is a non-profit international organization committed to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness.

Vision

TRIO is widely recognized and respected as the leading voice of transplantation, representing donors, candidates, recipients and their families. Through the TRIO Headquarters and a network of and members-at-large, TRIO serves its members in the areas of:

1. Support
   Providing support to transplant candidates, recipients, donors, and their families to help alleviate the stresses and problems associated with the process.

2. Advocacy
   Making the concerns and needs that affect the welfare of transplant candidates, recipients, their families and donor families known to federal, state and local government bodies. Effectively communicating the views of transplant candidates, recipients, their families and donor families on issues in the field of transplantation and organ and tissue donation to the general public.

3. Education
   Providing transplant candidates, recipients, donors, and their families with current information on developments in organ and tissue donation, transplantation, medications, social issues, and finances. Informing transplant candidates, recipients, their families and donor families on initiatives in the transplantation field by federal, state, and local government bodies.

4. Donor Awareness
   Promoting organ and tissue donation as an important social responsibility. Developing and supporting mechanisms to improve the availability of organs and tissues on an equitable basis to meet the needs of transplant candidates.
The Year Ahead

TRIO Advisory Boards
The TRIO Corporate Advisory Board (CAB) is comprised of past TRIO national Board of Directors members or corporate and community supporters of TRIO’s mission with special skills and backgrounds who wish to support TRIO without the more demanding responsibilities of serving on the national board of directors.

The Medical Advisory Board (MAB) is chaired by previous Board of Director member Tom Peters, MD. The MAB is comprised of doctors, nurses, nurse practitioners, social workers, OPO staff or other healthcare professionals affiliated with organ transplantation or who deal directly with transplant patients and families.

Post-Transplant Cancer (PTC) Initiative
Many studies now confirm that cancer is a major source of morbidity and mortality following solid organ transplantation and has become one of the three major causes of death after transplantation in the past decade. A recent study supports this issue further. Thus, knowledge of post-transplant cancer risks and options for prevention are critically important to all transplant recipients.

TRIO is uniquely positioned to take the lead in addressing this critical issue based on its long history of action supported by a broad spectrum of engaged transplanted organ recipient members and active chapters across the country. The PTC initiative is a comprehensive and innovative project educating recipients of their higher post-transplant cancer risk, identifying and encouraging best practices for living longer lives addressing that risk with early detection and proactive steps preventing and dealing with post-transplant cancers (PTC).

The developing project can be reviewed at www.triowebptc.org.

TRIO E-News
Each month TRIO publishes an on-line newsletter. This e-communication provides members and others in the transplant community an update on activities and events. The monthly TRIO e-news is also available on-line to the entire transplant community through links on the national web site https://TRIOweb.org.

Transplant Presentation Library
The Transplant Presentation Library is now into its seventh year, serving as an aid to TRIO chapters and the general transplant patient community, providing professional informational presentations. The presentations are posted on-line at www.trioweb.org under RESOURCES (https://www.trioweb.org/resources/transplant-presentation-library-dvd-program.html).

Chapters
TRIO Chapters, located across the country, serve to educate members and the public in general. Along with local social events and unique annual special events, Chapters hold monthly or bi-monthly meetings, provide speakers from the medical
community to provide up-to-date information and to discuss changes within the transplant community, and participate in transplant related activities to promote awareness and donor education.

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.

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.

Public Policy
The TRIO Public Policy Committee continues to engage in a number of activities, including participation in patient coalitions and advocacy groups and the Transplant Roundtable which represents numerous Washington-based transplant organizations, Friends of HRSA which represents groups that work with the federal agency that regulates transplant programs, and Waitlist Zero which advocates for increased living kidney donation TRIO works with the Partnership to Protect Part D Access through membership ‘calls to action’ and letters to Congress and the Administration to oppose changes which would remove protected class status for immunosuppressant drugs in Part D plan formularies. TRIO participates in attending meetings at the Health Resources Service Administration to support advocacy efforts by Waitlist Zero and bring attention at the federal level to the needs of post-transplant patients. TRIO is a co-signer and active supporter of the Honor the Gift campaign supporting legislation to extend the current 36 month limitation to free drug support for kidney recipients.

In 2020, TRIO will continue our participation in these various coalitions and engage in activities to support the passage of the recently introduced Living Donor Protection Act, which provides supports and protections for living donors. In broader terms, we look for ways to support TRIO’s goal of increasing recipient awareness of post-transplant cancer issues, to find opportunities to increase the health community’s understanding of the special needs of past transplant patients, and to increase understanding and engagement in public policy at the TRIO chapter and individual member level by developing tools, educational materials, and resources about both the importance of and action planning to influence ongoing national policy determinations.
Public Awareness/Event Participation

Many TRIO members and chapters participate in public events. For instance, the TRIO Ventura County/West Valley Chapter and the San Francisco Bay Area Chapter provide volunteers to decorate the float for the Rose Bowl Parade. The Donate Life America float focuses on raising awareness to the shortage of organ donations. In April of each year, many TRIO chapter members visit churches, temples and mosques across the United States to help promote organ and tissue donation. Another example is TRIO Long Island Chapter’s recognition of donor families in an annual rose garden ceremony. In yet another annual event, TRIO Manhattan Chapter hosts a donor recognition ceremony at St. Patrick’s Cathedral each spring with recipients honoring donor families in this special ceremony. Many TRIO chapters provide volunteers to promote organ donation awareness and provide information to personnel at state DMV registration facilities as well as speakers for medical staff training and local civic organizations/groups.

Airline Flight Assistance

TRIO is pleased to be one of only 41 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.

A Plan for the Future

TRIO’s Strategic Plan continues to guide the organization in moving 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

Look for your own role to play as a local chapter leader and active participant in this 33 year old important patient support movement as we continue into 2020.