

TRIO Supports:



www.donatelife.net

Lifelines

April 2010



Transplant Recipients International Organization, Inc.

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

www.trioweb.org • info@trioweb.org • 1-800-TRIO-386

TRIO Chapters Celebrate Donate Life Month in April

National Donate Life Month was established in 2003. Every day in April, people across the U.S. make a special effort to celebrate the tremendous generosity of those who have saved lives by becoming organ, tissue, marrow, and blood donors and to encourage more Americans to follow their fine example. TRIO chapters work diligently to promote organ donation all during the year. However, in April, chapters make additional efforts to sponsor events, participate with other organ donor partnering organizations and promote organ donor awareness.

Below are some Donate Life Month highlights sent by TRIO chapters across the nation.

Akron-Canton Chapter members will be attending an Organ Donation Service on April 16 at Temple Israel in Akron Ohio. Members report that at previous donor services, the Rabbi asked recipients and TRIO members to raise their hands. That made quite an impression; there was a gasp in the congregation when people realized how many of those present benefited from or were touched by organ donation.

The TRIO **Long Island Chapter** is commemorating Donate Life Month by participating in more than a dozen events in April. These dedicated volunteers are teaming with their coalition partners, including state Senators and members of the General Assembly, the New York Organ Donor Network and Transplant Centers to help save lives and truly make a difference. The festivities and events throughout the month will be followed by a trip to the state capitol in Albany, NY, on April 27. There the chapter members will meet with their legislative representatives to seek support to improve the New York State Donor Registry of Consent, institute donation education in high schools and encourage state tax incentives for financial gifts to support organ and tissue donation research and outreach. (See full

article in this issue, on page 6, discussing these legislative initiatives in more detail.)

On Saturday, April 10, the TRIO **Manhattan Chapter** will hold its fifteenth annual Ecumenical Service to "Remember and Rejoice." The service, usually drawing about 1,500 attendees, is held at St. Patrick's Cathedral in New York City. The chapter invites everyone to come join us as we "Remember" our donors and their families who so generously have given the "Gift of Life" and "Rejoice" with recipients who have received this special Gift.

On April 25, the TRIO **Nation's Capital Area Chapter** will participate in the Donor Recognition Ceremony, sponsored by the local OPO, the Washington Regional Transplant Community. During this non-denominational event, small recognition gifts are presented to donor families and living donors. During the reception following the ceremony, recipients and their families have an opportunity to personally thank all donors.

On Saturday, April 3, TRIO **Northeast Florida Chapter** will hold its sixth annual Donate Life Day on the Jacksonville riverfront. This free, family-friendly event features a full day of live music, fun activities and compelling speakers and video presentations centered around organ and tissue donation and transplantation.

The goal is to register organ and tissue donors and provide public education and awareness of the need for donation.

Donate Life Day
on the Riverfront,
Jacksonville, FL



(... article continued on page 3)

President's Message



J.T. Rhodes

Hope you are full of life as Spring is here!

Have you thanked your donor family for their gift of life? If not, contact your transplant coordinator on how to write the thank you letter. It might be a hard letter to write but so many donor families have told me how they would love to hear from the recipients of their loved one's organs.

As you read this edition of *Lifelines*, you can see how busy TRIO and its chapters are in promoting donor awareness and helping transplant recipients. You should be proud of what TRIO chapters are doing during Donate Life Month. Thanks to all the chapters who are working so hard on one of TRIO's missions: donor awareness. Hopefully, TRIO will sign many donors to registries and help people along their path of becoming organ donors.

Your TRIO board read with interest an article about primary care physicians not discussing organ donation with their patients. As a result of hard work by Jim Gleason, TRIO is starting a primary care physician awareness program. We plan on working with CORE, an OPO in Pittsburgh, on this project. The Philadelphia chapter will start a pilot program that will then be refined for other TRIO chapters. The program plans to have you, as a recipient, making your primary care physician aware of the need to discuss organ donation with their patients and giving them the information to pass on to potential donors. Look for more on this program as it develops.

On April 30-May 1, TRIO will hold a "Leadership Summit" for chapter officers at the Gift of Life Donor

Program offices in Philadelphia. The program consists of a full day and a half of training and interaction among local TRIO officers and leaders. The presentations will focus on ways to help your local chapters and to make TRIO a larger part of recipients' lives. Scholarships will be provided for reimbursement of part of the costs of attendees for transportation and hotel. These scholarships will be paid by TRIO National, from a program grant received from Genentech/ Roche, as a form of thanks for all the hard work that your chapter leaders do for your chapter. We are expecting a very good turnout for this free event. Time is fast running out, so please send in your registration form soon! Again, thanks to Jim Gleason and the Philadelphia Chapter for making this event a reality. (See the article on page 5 of this issue of *Lifelines*.)

The "Focus on Youth" program is gaining steam. Valen Cover and Holly Werlein are working hard on the TRIO Youth Circle. An article on page 7 of this issue introduces you to this new TRIO program.

TRIO is also working to establish a virtual group to unite our Members at Large. If you are interested in helping get this group started, please contact our managing director (sleach@trioweb.org).

On TRIO's website is information on how to support the new legislation on extending kidney transplant drug coverage. This coverage is the starting point for coverage of medication for all organ transplant recipients. Hopefully, after this law passes, TRIO can work on showing how important it is for ALL organ recipients to have immunosuppressive drug coverage.

If you haven't visited the TRIO website lately, please do! It is full of great information about transplantation and what TRIO and its chapters are doing.

TRIO will have a booth at the Transplant Games in Madison, WI, July 30-August 4. Be sure and contact your chapter president if you would like to help at this booth. If you are planning to attend the games, stop by the booth and say hi!

Lifelines is published quarterly by Transplant Recipients International Organization, Inc., 2100 M St., NW, #170-353, Washington, DC 20037, 800-874-6386, www.trioweb.org.

Lifelines is published by the Newsletter Sub-committee of the Communications Committee. The Newsletter Subcommittee consists of Pat Beeman, J. T. Rhodes, Elizabeth Rubin, and Dr. Tom Peters, Advisor. Editor: Sylvia Leach.

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106,599 people were on the waiting list for transplant LAST WEEK!
You can check the seriousness of this matter by daily logging in to
UNOS (www.unos.org)

TRIO Chapters Celebrate Donate Life Month in April

(. . . continued from page 1)

The TRIO **Philadelphia Chapter** supports Donate Life Month by doing speaking events for civic organizations, schools and medical classes in local medical schools, by participating as a Team TRIO in the Gift of Life's 15th annual 10K Run/Walk DASH for donor awareness, and by sponsoring a TRIO table at the DASH event to promote awareness as well as encourage membership in TRIO.

TRIO Pittsburgh Chapter is celebrating Donate Life Month in several different ways.

"On April 1, we will have a Donate Life Flag Ceremony. On April 6, the Pittsburgh Penguins will hold an Organ Donation Awareness Night. April 8 will begin our first Candle Light Celebration for Donation where we will light candles to represent the 700+ local patients waiting for transplant. This will be at 7:30 pm on the steps of the City-County Building. There will also be candle lighting ceremonies in Harrisburg on April 1, as well as in Philadelphia. We will have Organ Donor Awareness Tables at UPMC Hospitals as well as at Allegheny General Hospital. Our annual Celebration of Life Dinner will be on Monday, April 19, at the University Club.

"Transplant Nurses' Day will be on April 21. There will also be Celebration of Life programs at both UPMC and Allegheny General to honor our Donors."

The chapter is also pleased to report that TRIO Pittsburgh Chapter received the *Tribute to Excellence* award presented by the American Liver Foundation on February 26.

The TRIO **San Francisco Bay Area Chapter** reports that "Donate Life Month in the San Francisco Bay Area got an early start on March 20 at Stanford University when Apple CEO and recent liver recipient Steve Jobs promoted a new state bill requiring applicants for driver's licenses to answer whether they would be organ and tissue donors before the Department of Motor Vehicles would issue their license. Those willing to donate would be added to the state donor registry. Jobs also talked about how he was advised to go out of state (he received an organ at Methodist University Hospital in Memphis, TN) due to the large wait lists for transplants in California.

The event was attended by a number of chapter members.

"Library displays during the month are another popular way of encouraging people to consider

donation, and we have several displays in cities where our members reside.

"On April 24, our organ procurement agency, the California Transplant Donor Network (CTDN), hosts a ceremony to honor the memory of those from the Bay Area who donated organs during 2009 and to thank the donor families. Our chapter always has a presence at this very emotional event."

In preparing for Donate Life Month activities, the TRIO **Southern New Mexico Chapter** will visit the majority of the auto dealerships in the Las Cruces area and present each dealership with a Donate Life poster. Several organ donor awareness events will be held at auto dealerships during Donate Life Month.

The TRIO **Ventura County/West Valley Chapter** reports that "members of our chapter will receive Proclamations from the cities of Santa Barbara, Goleta, Ventura, Oxnard, Thousand Oaks and Agoura Hills. These Proclamations will be accepted at each city hall by members of our chapter. The Proclamations will then be displayed at the 8th Annual Donate Life Run/Walk and at Department of Motor Vehicle offices. We have been doing this for the past few years.

"Donate Life posters will be displayed throughout our area. Members are speaking at various events throughout the month and also setting up Donate Life tables."

TRIO Services Survey - last chance!

Hundreds have responded, but don't miss your opportunity to be counted in our on-line **TRIO Services Survey** found on the TRIO website homepage (www.trioweb.org).

Analysis of members' responses will begin shortly with feedback to chapters in the weeks ahead. So, be sure your chapter and your individual voices are included in those results. This is a chance to express yourself relative to what TRIO National is doing for its members in 13 areas of service as well as an opportunity to tell us what else you think can be done to support you, our members.

TRIO is listening!

Are you taking this action to be heard?

New TRIO Communications Initiative Launched

In the pre-analysis of the ongoing TRIO services survey (see page 3) the one concern and suggestion that rose above all others was members' interest in receiving more direct communications from the national TRIO organization. As an immediate response to this issue, TRIO has initiated a new service that will supplement both the quarterly hardcopy *Lifelines* newsletter and the on-line TRIOWEB.ORG website with an e-mail blast of news and information of interest to all TRIO members on an as needed basis, typically monthly.

Though many will respond that they already get too many e-mails, it is the goal of this new resource to offer content of such value that members will look forward to receiving focused information that will make it easier for them to become healthier patients and more engaged with TRIO's mission, both at the local chapter level and even more so for the majority of members who are not regular meeting attendees or not associated with a local chapter. As with any e-mail, it only takes a simple keystroke to delete that which is not of interest. For this resource, you will always have the option of unsubscribing (at any time) with a simple checkmark at the end of the message.

This informational service is offered to all TRIO members, both chapter members and Members at Large. The e-mail informational distribution began last month for those TRIO members who have e-mail addresses in our national database. All chapters have been asked to advertise the availability of this new service, giving chapter members the option of submitting their e-mail address if it is not yet available in the TRIO national membership database. If you did not see the first few messages, then we do not have your e-mail address. If you would like to see what the messages look like, just send your name in an e-mail to info@trioweb.org and we will include you on future mailings, leaving you with that easy option to stop receiving ("opt out") at any time.

Note: As an alternative, to see a sample of the latest message content, go to the link offered on TRIO's website (www.trioweb.org) where you can view the message online without submitting your e-mail address.

Have You Seen One?

With ten presentations now released in TRIO's ***Transplant Presentation Library*** and eight more scheduled for the months to come, have you seen the titles available to you? Each TRIO chapter president has the library for you to take out these DVD programs to watch at home on your TV or computer. Members at large can contact Sylvia Leach (sleach@trioweb.org) to have individual copies mailed to you. The growing list of titles, along with the schedule for each release, is available on-line at www.trioweb.org. Check the website regularly to see what new programs are released and new ones scheduled.

TRIO Scholarship Application Deadline Is June 30, 2010

Each year, TRIO awards several \$1,000 scholarships to transplant candidates, recipients, their family members and donor family members. During the past 13 years, TRIO has awarded a total of 74 scholarships. In 2009, scholarships were funded by the TRIO Board of Directors, the Helen and Richard DeVos Foundation grant, the TRIO Greater Cleveland Chapter, and the TRIO Northeast Florida Chapter.

The 2010 application is available for download online at www.trioweb.org, under the "Communications" tab. At that location, TRIO has also provided links and information about other scholarship opportunities.

TRIO Scholarship funds are sent directly to the institution at which the applicant is enrolled.

To be considered, applications must be post-marked by June 30, 2010. Award notifications are made in the Fall.

Are You Taking Full Advantage of What TRIO and United Airlines Can Do For YOU?

TRIO is most fortunate to be one of only 20 organizations partnering with United Airlines to allow frequent flyer seats for transplant-related travel AT NO COST. Do you or someone you know need to travel for pre- or post-transplant related medical visits? Does a transplant recipient or living donor need to travel with a care-giver? This is an open, public program, not limited to TRIO members. PLEASE take advantage of this wonderful program, generously provided by United Airlines! Call 1-800-TRIO386, go to TRIO's website www.trioweb.org or email us at info@trioweb.org.

TRIO Leadership Summit to Convene in Philadelphia on April 30

An open invitation has gone out, through TRIO chapter presidents, inviting all TRIO leaders and potential leaders to participate in a 2010 leadership training event to be held from noon on Friday, April 30, through 5pm on Saturday, May 1, at the Gift of Life Donor Program offices in Philadelphia, PA. Two \$300 scholarships per chapter are being offered as a partial reimbursement for travel and lodging for those attending the event.



*Gift of Life Donor Program Offices
Philadelphia, PA*

The opening lunch keynote speaker is Howard Nathan, CEO and President of the Gift of Life Donor Program, who will share his personal success of turning dream into reality. Over the past 35 years he has taken a tiny one-man kidney transplant call center into the world's leading OPO and, more recently, capping that dream with a 35-bed Transplant Family House to provide temporary living space for patient families awaiting transplant, a dream you will see under construction a block away from the Summit event site.

Panels and workshops will be presented to develop leadership skills and share best practices in topics of "Engaging and motivating the volunteer," "Successful fund raising," "Re-energizing and re-inventing the local chapter," "Creativity in developing successful events," and "Grant writing at the local chapter level." Speakers and panelists from NTAf, ITNS and Gift of Life Donor Program will join with TRIO chapter and TRIO national leaders in these sessions.

There will be ample time for social interaction among attendees, learning what others are doing to make their chapters successful or how they are overcoming current challenges we all share. An optional inside tour of the Gift of Life facilities will be offered, including their world-leading training center, a state of the art donation call

center and even surgical suites for organ recovery on-site.

Friday evening offers an opportunity to attend a local heart transplant support group annual dinner dance. The cost is \$45 per person. Directions for reservations are on the Summit registration form.

A closing session focused on "What is your dream for TRIO?" will send everyone back to their local organization energized with goals and actions to make for a stronger TRIO chapter through this exciting sharing event.

Your registration is due by April 15. Check www.trioweb.org for the registration form and for more information on hotels, travel and the scholarships available. You may also contact Sylvia Leach, (sleach@trioweb.org), TRIO Managing Services Director, to register or get information.

What's New on TRIOWEB.ORG

With so much happening, how can anyone keep up with it all? Among the many resources supported by TRIO, our website is one answer to that question with its almost daily updates of news vital to the transplant recipient and anyone interested in the world of transplantation.

Among the more recent updates:

- RX news of interest offers several significant money-saving rebate opportunities along with recent medication updates, such as recent generic releases
- Legislative calls for supporting action by patients as federal bills move through their processes
- Totally new Youth sections offering opportunities for young people to get involved by sharing their inspiring stories and express their concerns
- News of new TRIO efforts responding to members' survey responses calling for more direct member communication
- A constantly growing index of Transplant Library Presentation Programs available to members (18 titles now available or scheduled for release!)
- Announcements of upcoming TRIO events such as the Leadership Summit and a nationwide campaign to engage Primary Care Physicians in raising organ donor awareness with their patients.

Check it all out at www.trioweb.org.

Organ Donation Awareness Legislative Initiatives – TRIO Long Island Chapter

The TRIO Long Island Chapter is very lucky to have dedicated volunteers making all of the following initiatives possible. We are pleased to team with our coalition partners inclusive of Senators, Members of the Assembly, NYODN, and Transplant Centers as we travel to Albany to help save lives and truly make a difference.

On April 27, chapter members will travel to Albany, New York, where we have scheduled appointments with New York State Senators and Members of the Assembly.

Our chapter will obtain New York State official proclamations that proclaim April 2010 to be forever known as and referred to as "Organ Donation Awareness Month" in New York.

We will be meeting with Assemblymen and Senators who are working with Long Island TRIO and our coalition partners in order to improve the New York State Donor Registry Of Consent. We will also seek support from Senators who have promised to meet with us as we teach them about the importance of New York State accepting "Electronic signatures" as legal consent in order to make an anatomical gift. This will help our chapter's volunteers who work throughout the year signing up new donors to the Donate Life Registry. We also have a legislative initiative that will ensure that the "Registry choice" is not skipped and that New York State will require all drivers (when renewing their licenses) to either check the box and register in the NYSDL Registry or check a box saying that they defer this decision to their families or a later date. We are also trying to accomplish another important goal; that is for New York State to eliminate the requirement of each person checking off specific body parts to be donated.

Our TRIO chapter has led the charge into the classrooms in hospitals, courts, universities, high schools and physician's offices and our LI TRIO speakers bureau has directly reached over 18,000 students in person in the classrooms to date. Our chapter is also seeking support for Legislative Bill Number: A. 292 (Magnarelli) and S.4373 (Oppenheimer) that will require health education regarding organ, eye and tissue donation awareness in every high school in New York State while cooperating with TRIO, the Transplant Community in New York State, and OPO's. These bills call for the requirement of thirty minutes of "Donation Education" in 8th or 9th grade school health classes in high schools. As New York State is asking the donation

question of every person applying for a license, it stands to reason that NYS would want its populace to be prepared to make an educated decision. The curriculum and all content and materials will be provided at no cost to all New York State high schools.

We are also meeting with Senators in Albany to seek support for legislation that will provide a tax check off box on personal income tax return forms for gifts for the Life Pass It On Trust Fund for gifts of organ and tissue donation outreach and research. Legislative Bill Numbers: A. 6190 (Titus) and S.4319 (Adams), and New York State is considering the following incentives as well:

It has been suggested that the registry be expanded to allow altruistic living donors to register and begin the assessment process. A tax credit would be implemented to help offset lost wages for living donors. This would require a change to the tax code. Legislative Bill Number A.214 (Jeffries) provides a leave of absence for employees in private business who are organ or bone marrow donors and insurance reimbursement to employers for wages and salary paid on such leave. Another bill - Legislative Bill Number A. 4265 (Ortiz) allows a person who donates one or more organs to another individual to receive up to \$10,000 tax deduction for non-reimbursed expenses. Our state is also considering a bill that would provide a funeral benefit or nominal state tax credit for deceased donor families to defray the time and any burial costs that may have been impacted by donation. As an example, Pennsylvania adopted a \$300 funeral credit or offset several years ago, but has never implemented this credit (to date) due to concerns that it may require federal legislation to overcome "National Organ Transplant Act" restrictions.

Our chapter has quite a full schedule of events for Organ Donation Awareness Month. We look forward to all of our volunteers making April 2010 a very special "Donate Life Month".

*-- Article submitted by Mike Sosna, President
TRIO Long Island Chapter*

UNOS welcomes your questions, requests,
comments and suggestions:

888-894-6361

The UNOS patient services staff is available to
help you Monday – Friday, 8:30 a.m. -5:00 p.m.
(Eastern Time)

When Pursuing a Living Kidney Transplant: It's About Your Donor Finding YOU!

Once your doctor informs you that you need a kidney transplant, they often recommend that you “find a donor.” What comes to mind is that they will have to “ask” someone to donate a kidney – clearly a very daunting undertaking. What’s surprising is that living donors report that they were not “asked” but they heard about a need and happily volunteered to donate to meet their family member or friend’s need.

So how do you start the quest to have the donor find you? It’s very important to start by learning as much as you can about your medical condition and the living donation process. The more you know, the more confident you’ll be when discussing the subject.

Once you are prepared with the knowledge about transplants and living donations, you’ll need to communicate this to your family and friends. The most effective approach is to be yourself and speak from your heart. The message should be concise, clear and personal - tell “your story.”

It’s common for family and friends to help spread the word about your conditions. These “advocates” provide invaluable support and can significantly increase the number of people who become aware of your need.

Letting people know about your need for a kidney transplant may initially seem overwhelming. However, once you get started it’s often not as difficult as you might imagine. Develop a plan and start by speaking to those close to you (where you will be most comfortable). The more people you speak to, the easier it will get and the greater your chances will become of *a donor finding you*. Donors often come from the most unlikely connections (but you’ll discover they are really not unlikely at all). Reach out to everyone you know - because each of them has an extended network that might hear of your need and step forward. There are more than 16 successful living kidney transplants performed every day in the U.S. Perhaps the next story about a living kidney transplant will be yours!

- The above article is presented by Harvey Mysel, a kidney transplant recipient, and Founder of the Living Kidney Donors Network offering workshops to educate people in need of a kidney transplant about living kidney donation and helps prepare them to effectively communicate their need to family members and friends. The Living Kidney Donors Network website is: www.lkdn.org, email at: harvey@lkdn.org, 312-473-3772.

TRIO’s Youth Circle Empowers Younger Transplant Patients



Are you a young transplant candidate, recipient, donor, or family member looking for support? If so, we encourage you to join our new group – TRIO’s *Youth Circle*!

The *Youth Circle* is committed to empowering people, especially younger people, to never lose hope, and to improving the quality of lives touched by the miracle of transplantation through support, advocacy, education, and awareness across the youth community.

It is important for youth to have a strong support system and to know that they are not alone. Our goal is to form a virtual group that will unite youth and their families, provide a positive and inspirational environment to share thoughts, grow, and learn from each other.

The *Youth Circle* is here to proudly show that transplantation works and that we can live a wonderful and fulfilling life with the special gift we have been given.

Please visit www.trioweb.org and click on the “Community” tab, then on *Youth Circle* to learn more about this exciting new group. On that website page you can read inspirational stories of younger transplant recipients and you can share your own personal story. In this section, you will learn more about the leaders of *Youth Circle*: Valen Cover and Holly Werlein. You will also find a question and answer section, where we encourage you to ask questions and you will receive answers from people who have first-hand experience with transplantation.

TRIO’s new “Youth Column” will be published in each issue of *Lifelines* to discuss issues, concerns, and topics that relate to youth. Do you have a topic that you would like to learn more about and want to see in the next *Lifelines* issue? If so, please e-mail your topic ideas to Valen Cover (PKDwillnotbeatme@yahoo.com) and Holly Werlein (hwerlein@hotmail.com).

Are you finding it difficult to connect with others your age? If so, we encourage you to join our TRIO *Youth Circle*.

Time and Location for TRIO’s Next Board of Directors’ Meeting will be announced soon.
Check www.trioweb.org

Membership – NEW and Renewal: TRIO membership is renewable as of January 1 each year. Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: _____

Names of other family members: _____

Address: _____

City: _____ ST: _____ ZIP: _____

Phone: _____ Fax: _____ email: _____

Member is: ___ Recipient; ___ Donor; ___ Candidate; ___ Family Member; ___ Other: _____

Recipient Profile (Optional): _____

Type of Transplant	# of Transplants	Date(s) of Transplant(s)
Name of Transplant Center(s)	City, State	Time Waited

Donor Profile (Optional): _____

Type of Donation	# of Donation(s)	Date(s) of Donation(s)
Name of Transplant Center(s)	City, State	

I would like to participate on the _____ TRIO Committee. Please contact me.

Annual Dues: Member at Large \$20.

Additional Contribution \$ _____.

TOTAL enclosed \$ _____.

Thank You for your tax-deductible donation!

Make your check payable to and mail to:
Transplant Recipients International Organization, Inc.
2100 M St., NW, #170-353
Washington, DC 20037-1233

PLEASE NOTE: If you are a member of a TRIO chapter, please pay dues to your local chapter instead of submitting this form. If you are not a member of a TRIO chapter, please consider joining a local chapter to receive the many benefits of chapter affiliation. TRIO National strongly supports local chapter membership. A list of chapters is available on our website www.trioweb.org. OR: consider starting a transplant support group or TRIO chapter in your area (contact info@trioweb.org).

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