

TRIO Supports:



www.donatelife.net

Lifelines

April 2012



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

April is Donate Life Month . . . Are You Remembering Your Donor Family?

As you are reading this *Lifelines* issue, ask yourself the question: "What are you AND your chapter doing to remember donor families this Donate Life Month?" You have read about the Manhattan chapter's annual "Remember and Rejoice" donor recognition ecumenical service held in the huge St. Patrick's Cathedral, NYC (this year to be held on April 14th). Each September the Long Island chapter hosts another major donor event in their famous Long Island rose garden.

What does your chapter do, maybe not on that grand a scale, but in a way appropriate to your resources of attendees and funding? If that answer is something inspiring, share a photo for posting on TRIO web news. If nothing is on your yearly chapter calendar, maybe now is the time to suggest an event or brainstorm ideas within your chapter.

Board member James Mateiko is the chair of TRIO's donor family committee. In recalling his own beautiful mother's donation upon her sudden death, James suggests this topic for your thoughtful consideration this April. Perhaps, for now, it's just time to remember your own donor during this very special month or taking time for a letter of thanks to your donor family, whether or not you know the family or, like most, an anonymous note sent through your transplant center or local OPO. Or, maybe it's a speaking event where you share that gratitude publicly, encouraging others to take action on their own organ donor designation.

Whatever your situation, James offers these thoughts for your consideration, along with an invitation to join him in developing this donor committee for future activities.

Drop James a note at info@trioweb.org if interested or have ideas to offer.



TRIO's 25th Anniversary: A Major Change In Plans!

Overall response to the recent member survey of interest in the announced September 25th Anniversary big conference event fell far short of the minimum needed to host that event. The Anniversary planning committee, based on that member message, has recommended to the board that we not move forward with that event. The board agreed and is developing a plan to offer a "Leadership Summit 2012" instead, building off the successful model of the last two years, marking the 25th anniversary at the Leadership Summit with a scaled-down celebration dinner the first evening of that two-day workshop.

The recommended site is still Pittsburgh, the 1987 birthplace of TRIO. The summit dates *will most likely* be the same: Friday and Saturday, September 28 and 29. New event details will be sent out in the weeks ahead.

If you weren't able to attend the 2010 or 2011 summits, this may be the opportunity you were looking for, so check out the videos of the 2011 summit still available on the TRIO website. We hope again to share anticipated grant funding support with attendees through \$300 scholarships to help offset some of the travel and lodging expense for any who need. That will be confirmed when grant applications are approved.

See Inside:

TRIO Discusses Wall Street Journal Article: Page 3

TRIO Member Fights Supreme Court: Page 4

TRIO Chapter Publishes Children' Book: Page 6

PLUS updates on Presentation Library, Website, Virtual Chapter, Primary Care Physician Program, along with many other interesting articles. Find out what's going on in TRIO!

President's Message



Jim Gleason

Life Begins When You Do!

A special welcome to the many new TRIO chapter officers across the country who are taking up the challenge of leadership in their local chapters. For some, there is a daunting but fresh energy opportunity of following in the footsteps of pioneers who have served for many, many years. For others, a successful process of succession planning has provided a smooth transition of service while former officers move into roles of mentorship and support.

TRIO needs that growth and change to remain fresh and vital, be it planned or a reaction to unexpected loss. Every leader should have, as one of their responsibilities, a plan to discover and develop future leaders as their support team and potential successors. That is true at all levels, local and national. Currently we are interviewing TRIO leaders to develop a supporting 'best practices' guideline to help with this process of "Succession Planning" as well as several other critical areas where we can learn from each other's mistakes and successful practices. Conducting effective chapter meetings, membership recruitment and retention, engaging the volunteer, effective use of 'social networking' are some of the challenges leaders have suggested as topics for this research and communication. If you have thoughts to contribute or other issues to add to this long term research list, please send them to me at info@trioweb.org for consideration.

Please seriously consider the invitation found in this issue to self-nominate as a 'chapter champion' and become the active pipeline between your local chapter and the many TRIO national initiatives. On a regular basis, these chapter champions will receive e-mail communications focused on that particular topic through which they can provide information to their chapter meetings/newsletters, each with a specific request for action and a question or solicitation to solicit and return with chapter members' feedback on that topic or issue. Chapter presidents would be copied on all chapter champion communications so they will be tuned into and can help support and guide their chapter champions in carrying out this responsibility.

April, of course, is again Donate Life Month. See the challenge of personal action in support of this great annual event in this issue. Read also how TRIO members are supporting UNOS in its mission of overseeing and managing the donation process that is both protecting the wishes of donors and saving the lives of recipients each and every day. TRIO is an action and service organization that offers its members the opportunity to express their gratitude for life saving gifts in ways that most individuals would not find possible except with the support of resources TRIO chapters and a national organization offer, action and service that help change the world in a very unique giving way.

I leave you with this information filled *Lifelines* issue that hopefully will serve to inspire you to new levels of that service and action. Read and take action. Find your own special ways to contribute to that force of action-based gratitude that will both honor our donors and help the many on the waiting list for the chance that most of us are living with today--that gift of life through organ donation and the medical miracle of transplantation!

Yes, life begins when you do, so choose to begin now, living your life to a new inspired level.

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, Jim Gleason, J. T. Rhodes, Elizabeth Rubin, and Dr. Tom Peters, Advisor. Editor: Sylvia Leach.

Disclaimer: All contents of **Lifelines**, including text, graphics, images, information obtained from other sources and contributors and any other material, are for informational purposes only and not intended to be a substitute for medical advice, diagnosis or treatment. Neither **Lifelines** nor TRIO recommends or endorses any specific tests, physicians, products, procedures, opinions or other information in this publication.

Did you know?

There are 113,645 waiting list candidates!

Visit www.unos.org to see TODAY's number!

UNOS Resources

UNOS welcomes your questions, requests, comments and suggestions:

888-894-6361

(Monday-Friday, 8:30 am – 5:00 pm; Eastern Time)

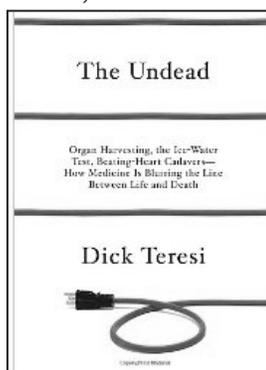
Wall Street Journal Article: To Respond or Not – That is the Question

Did you see or hear about this article that appeared March 10th (updated 3/13) in the Wall Street Journal (WSJ) that caused such controversy about brain death and organ donation?

As seen in the “Comments” section, more than 572 comments about that article have been posted as of this writing from all kinds of view and people.

Book author, Dick Teresi, raises questions about the way people are declared dead and in doing so, challenges the whole organ donation process in ways that are very detrimental to public opinion about registering as an organ donor. Obviously he is promoting sales of his new book, **The Undead**, which

recently came out. I have reluctantly ordered/read that book (not wanting to increase sales), so I can talk first hand about his positions and see the details behind the “facts” he offers, a book I doubt many will buy or read in its entirety. Let me just say that this article is an



accurate summary of his book, conveying in 300+ pages what he says in that much shorter WSJ piece. To understand the controversy in detail, look to the TRIO website to read his article. There, now you know what his book says. Want more? A link to the author’s NPR “Fresh Air” radio show interview that also includes a transplant surgeon’s response to points raised in that show can be found along with a full set of resources under “Special News” on the TRIO website home page.

As TRIO president, I was faced with the decision to respond to that article or not. At first, I felt that responding would just add publicity to it and his book, and that wasn’t in our best interests. Then people started asking what TRIO’s response to that article was, to which I explained that position. When other major organ donation organizations called to ask the same question as they tried to form their own response strategy, I felt TRIO needed to speak out and offer leadership and so changed that “no action” plan, suggesting instead that a formal collective response be drafted by professionals in the field that TRIO and other groups might co-sign, adding our combined weights to that message. When a draft was developed, TRIO reached out to our board’s medical advisor, Dr. Tom Peters, for his review



(www.WSJ.com)

and counsel. Tom recommended that we support that document, and with board discussion and approval, TRIO offered to join in supporting that AOPO (the national Association of Organ Procurement Organizations) response to the WSJ. In it, we clearly address the key points of brain death determination as a patient is protected both by law and the various parties that participate in that process. Again, look to the TRIO website for the full document, along with NKF’s official response to the WSJ.

Why do you care? As TRIO members and transplant-experienced individuals, people turn to you for answers when such controversies arise. As public speakers addressing many groups, we need to be prepared to respond when someone raises that issue with facts and confidence to counter the impact of misinformation that articles and books like this put out there causing fear and distrust if we aren’t prepared to answer.

Learn the facts by reading the full set of background resources on the TRIO website that include talking points responding to each issue so you will be able to respond from a confident position of strength when that opportunity arises.

-- Jim Gleason, President
TRIO Board of Directors

Donate Life America Seeks “20 Million in 2012”

TRIO members are encouraged to join the “20 Million in 2012” campaign by becoming a Donate Life America Facebook fan to keep updated on the 2012 events. Through this program, DLA seeks to register an additional 20 million people in 2012 on their state donor registries.

To be a part of this initiative, go to www.facebook.com/DonateLife. Individuals can join their state donor registry by visiting www.DonateLifeAmerica.org

TRIO “Little Guy” Fights Back

German (Herman) Vivas, a kidney hemo dialysis/transplant patient since 1997/2002 and active member of TRIO NE Florida Chapter since 2004 is not one to “mess with” as evidenced by his long time battle that now has him self-representing at our nation’s Supreme Court level.

German explains that the stakes are high because pre- and post- organ transplantation patients are part of the “high need, high-cost populations—both Medicaid-only and those who are dually enrolled in Medicaid and Medicare” as quoted from a *Report to the Congress on Medicaid and CHIP* to the Honorable John A. Boehner Speaker of the House U.S. House of Representatives.

German’s disability was determined by the Social Security Administration with chances of survival being put into jeopardy once again when Medicare Part D was introduced in 2006 because access to continuous, affordable medical care for Medicare-Medicaid dual eligible became like a Rubic’s Cube game. Complexities such as accessible life saving prescriptions became unobtainable because of out of pocket cost if the patient did not meet the threshold *share of cost* in each and every month of the year for the Florida Medicaid’s Medically Needy program.

What began in lower agency hearings has led to his six year paper chase to solve the Rubic Cube’s disarrangement leading to one conclusion: the Medically Needy program was no longer an option and pursuant to the “best interest of the applicant...” So, German chose a different category that has the Florida Medicaid plan accountable under the burden as obligated for receiving the Grant to States for medical assistance pursuant to Title 19 of the Social Security Act.

The wait will not be long. A conference date of March 23, 2012, is scheduled so the Court’s discretion can be applied in total secrecy as to whether the “Supremacy Clause” of the US Constitution and “category choice” applies in this case.

Obviously, there is much legal detail behind the story. You can find the report online at:

<http://www.macpac.gov/reports>.

A press release fact sheet can be found at:

<http://www.macpac.gov/home/press-release> and:

<http://www.supremecourt.gov/docket/docket.aspx>

To share your own related experiences, contact German Vivas at Gvivas927@att.net

-- German Vivas, Member,
TRIO Northeast Florida Chapter

2012 Transplant Games Of America: July 28-31

Register now for the 2012 Transplant Games of America coming to Grand Rapids, Michigan, on July 28-31, 2012. When the international games were cancelled early last year, a small group of local recipients joined forces to help save the games. We felt that the Transplant Games were integral in communicating the importance of organ donation and highlighting all of the advances in the transplant technology. I serve as special advisor on the steering committee and in that capacity I work with all of the committees in an effort to make these games a success. As a young liver recipient, helping put on the event is a wonderful opportunity to show my passion for organ donation. The West Michigan Sports Commission, a 501(c)3 non-profit, is producing the 2012 Transplant Games. Most of the sporting competition will be held at Grand Valley State University in Allendale, Michigan, just a few short miles from Grand Rapids.

All qualified organ recipients can participate in the games regardless of where they live-including our international guests. Athletes and team leaders are encouraged to check out the website for eligibility requirements. Living donors are now eligible to participate in all individual sports (all registrants should make sure to check each individual sport requirements for further clarification on general eligibility). Opening and closing ceremonies will include a moving tribute to honor of our true heroes-donor families and living donors. The weekend will be packed with special events for all, including a golf outing, barbecue, and much more. Whether you’re an adult or a kid, there’ll be something for you. Check out the website for additional information:

www.TransplantGamesofAmerica.org .

Register now! You don’t want to miss this heartfelt reunion. Be a part of our mission to spread awareness of the importance of organ donation and show the legacy that lives on through the gift of life.

--Holly Werlein
Member, TRIO Youth Circle

TRIO Board of Directors Quarterly Meeting

The TRIO Board of Directors held its quarterly meeting by teleconference on February 25. The next board meeting will be held by teleconference on May 12. If you are interested in attending, please email info@trioweb.org .

Living with Diabetes Post-Transplant

(This is the third in a series of articles about Diabetes. The first was “Are You At Risk?”, published in the October 2011 issue, and the second in the series “Recognizing Symptoms” was published in the January 2012 issue.)

Reportedly affecting approximately 15 to 20 percent in the first year post transplant, with still more facing late onset diabetes as a side effect of some of our life-saving medications, the challenge of living with and effectively managing blood sugar levels is often added to the daily concerns of post transplant life. Diabetes can be life threatening and certainly comes with severe complications if not recognized and treated effectively, so recognizing it is a critical first step as described in the previous article in this series. Once diagnosed, with today’s modern resources, managing diabetes can be very reasonable as an addition to the self-disciplined life of the average transplant recipient who already takes a large mix of timed medications and carefully follows up in their daily lives.

The first step is to take advantage of the excellent educational programs offered by local diabetes centers, most covered by insurance. I was fascinated by the explanations of how the body deals with sugar carbohydrates, both normally and in the diabetic condition. One doctor friend described my situation as: **“You get to be your own manual pancreas, doing what the healthy body does automatically but now intentionally yourself in its place.”** With careful attention and that education, this becomes a very effectively managed condition. For many, today’s drugs can maintain the proper balance of sugar intake with body processing of the needed insulin. For others, myself included, now almost 18 years out from heart transplant, it is necessary to manage the body’s sugar levels with injected insulin. In that class you learn how to come up with specific metrics for your particular body. Once you know that number, for an insulin dependent diabetic you test blood sugar levels before and after each meal, taking a painless injection of insulin that is calculated to “cover” the carbs in the food you are about to eat. The goal is to mimic what the healthy body does that keeps your blood sugar levels as close to 100 as possible based on blood tests taken two hours after each meal. It helps if you are comfortable dealing with numbers since this truly is a numbers game. Too much insulin and you can suffer dangerous sugar lows in danger of fainting, while too little and you test as having high blood sugar levels that could lead to organ damage over time.

Typically you will use a once-a-day long lasting insulin supplemented with the fast acting injection that is taken about 15 minutes before each meal. If you are used to managing the typical post transplant meds, adding this to the routine really isn’t as hard as it sounds. If you had told me years ago as I watched a relative give self-injections that I would be doing that painlessly myself some day, I would not have believed you. But with today’s fine needles, it truly is a painless procedure.

While it is possible to eliminate diabetes with weight loss for the overweight individual using exercise and careful food management, that has not been my solution yet, but I keep working on that with my diabetologist’s encouragement. I make regular visits to a podiatrist to watch for foot damage, an eye doctor to check for diabetic eye damage and quarterly checkups with that diabetes doctor who checks a history of metered blood level readings and a blood draw test known as your A1C. The A1C is a magic reading that somehow tells how your blood sugar levels have been over the past 30 days. With a normal range of 5 to 8, mine, for example, is a very well controlled 6.0, excellent for my age as he always tells me. Following these routines of daily management and regular medical care, while diabetes certainly is a serious disease, it can be controlled and not have a detrimental effect on your quality of life and overall life expectancy. But ignored, that can be a totally different story. With over five years of a very positive insulin dependent diabetic experience, I offer living testimony to those optimistic outcomes, but then too I have seen the devastating effects in others when this condition is not managed and that is not pretty. In conclusion, if you become diabetic, with careful care and self-discipline, yours can be an active, fulfilled life, but you have to remain in control as your own “manual” pancreas. While each story is unique, I wish for you the very positive outcome that I enjoy each and every day with my transplanted heart and insulin-controlled blood sugar levels.

—Jim Gleason, President, TRIO Board
Heart Transplant Recipient: October 19, 1994

(Note from the author: This article was written at 2am as I was awakened with a low blood sugar level of 43 --much too low due to over compensating for an earlier evening snack with too much insulin. I then enjoyed some fast sugar-raising orange juice bringing that level to a normal 100+ range. Oh, and meant to add, when your sugar is low, those around you may notice, but you wouldn’t, that you are very irritable and short tempered. So be careful, that could damage both health and relationships.)

Facilitating Self-Care Behaviors Pre- and Post-Transplant

The average transplant recipient can spend months to years anticipating an organ transplant, hoping for the day that could provide them with a second chance at a healthy life. For many patients and their families, life can come to a complete standstill while they wait and develop coping strategies and mechanism to endure the passing of time and assume new roles of “patient and caregiver.” Little time is afforded to envision and imagine what life after transplant can be, which can leave patients and families with no clear road map to face the life they await.

The rigorous post-transplant regimen patients and families must follow for months after discharge further impedes the opportunity for roles to transition as the focus is intensely on restrictions and recovery. However, the goal of a transplant is to return, or become as independent as possible, after medical clearance is given, which is often easier said than done. For many, becoming disabled was in and of itself very difficult to accept. For families, becoming responsible for caring for a loved one who was once an equal is much the same in difficulty. Thus, restoring pre-illness roles is fraught with complexity.

Studies have shown that patients who obtain self sufficiency and self management experience better and higher quality of life (Journal of Advanced Nursing, Volume 66, Issue 4, pages 828 to 838, April 2010). The study concluded that patients, their caregivers and patient provider relationships were all highly satisfying in direct correlation to patient self management. In other words, relationships improved when recipients were as independent as possible because it allowed a return to normalcy, however that was defined by the family.

Transplant teams should incorporate strategies that enhance self efficacy into the period of time both pre- and post- transplant. This could include interventions designed to maintain and improve independence at every opportunity and should be a mainstay of the recovery period conversation. Patients and families should, at every step of the way, define and redefine what they can do within their family system to take back or give up responsibilities. The scope of self care goes beyond taking medication and includes nourishing the soul, actualizing dreams and living life as you and your loved ones imagined. For strategies and goal setting, consider

partnering with your transplant team’s social worker or a behavioral specialist.

A happy, healthy and self efficient 2012 to everyone!

*--Elizabeth Shore, MSW, CSW
Member, TRIO Board of Directors*

TRIO Recommended Readings: NEW, FREE Transplant Book For Children

“Mommy Can Play Again”

has just been published by the TRIO Philadelphia Chapter to help children understand transplant when another member of their family is about to undergo that process.

With children autographing their work, a press conference was held in February with the first copies being donated to the new Transplant Family House recently opened by the local OPO. Since its release, the book has been getting rave reviews from coast to coast and is being considered for possible submission to several national children’s book award programs.

This true story of a local mother’s double lung transplant is written at a child’s reading level with 36 pages of colorful illustrations done by children of the chapter’s member transplant families. In addition to the story, the book features a list of activities for children as well as many supporting resources for adults along with photos of the authors and illustrators. This fun project offers the free book on-line at <http://trioweb.org/MommyCanPlayAgain.pdf> for home PC viewing or printing. Also offered without charge, a limited supply of hard copy books are available for the asking from the Philadelphia Chapter.

Be sure to check out our ever-growing 100+ book review database under “Resources” on the TRIO website.

Scholarship Submission Deadline Approaches

The deadline for submission of applications for the fall 2012 TRIO scholarship competition is June 30, 2012. An application is available on TRIO’s website (www.trioweb.org). Click on “Communications.”



Transplant Presentation Library Adds New Heart Programs

Hopefully you are using the updated Presentation Library web page (look under “Communications/Resources”) for the link to track new monthly titles which now include:

- “Transplant Recovery Through Creative Endeavors”
- “Safe Medical Practices with Medication”
- (coming) “Health Screenings for the Healthy Lifestyle Long After Transplant:
- (coming) “2012 Update of Transplant Technology”
- (coming) “Good Nutrition Made Easy for Transplant Caregivers:

As we close out Volume III this June with 36 DVD programs offered, we look forward to grants to support a fourth volume of twelve new monthly programs for chapter distribution. Ask for any title through your chapter, or if you are a Member-at-Large, request directly from info@trioweb.org. As a TRIO member, you are entitled to take home any of the DVDs free for private viewing.

TRIO’s PCP Program: “Doctor, do you talk to patients about organ donation?”

The TRIO PCP (Primary Care Physician) process is really just that simple and anyone can do it. Your own transplant is exactly the supporting evidence that will make that question spark the conversation that will gain cooperation of physicians all around the country in addressing that topic with their patients. With a supporting TRIO physician’s brochure and informational pamphlets put out by Donate Life America, you will have the resources to make it easy for them to cooperate and raise awareness. That is our goal. The simplicity of our grass roots approach should succeed where others have failed, but that will depend on TRIO member participation.

Ventura County West Valley and the Philadelphia chapters have named champions and agreed to test market the approach. In the meanwhile, all chapters are being invited to name their PCP chapter champions to carry the message and process to local members as this develops and takes on momentum. Are you that person? Talk to your chapter president to offer your service to this important new initiative.

MALs: Stay tuned for your role in this program.

TRIOweb.org Update: “All the News That’s Fit to . . . “

How do you keep up with the daily news and issues that impact our organ donation and transplant mission? Whether its “**Donor Chains and the Legality of Compensating Kidney Donors: Critically Assessing Our Moral Intuitions**” or the WSJ article that is causing such a stir (“**What You Lose When You Sign That Organ Donor Card**”) every day there are important issues and developments that affect both our own lives or our ability to respond to audience questions that come up when we are out in the public advocating for our cause. The information flow never stops, so the question is how to keep up with it all, or how to find the news when it comes up after the article has passed.

The TRIO website posts news items and articles of critical information as soon as they arise. We keep it there, organized for quick reference, just a click away, current news highlighted on the home page for ease of use, all archived for easy reference later in topic categories.

Also, if you are looking for links to transplant resources or the latest chapter contact information, it’s there too--just one click away and kept current just for YOU! If you have suggestions or news to share, write to info@trioweb.org and see it on the website, usually that same day.

Dick Becherer, President of TRIO Akron-Canton Chapter

On February 8, TRIO was saddened to learn of the death of Dick Becherer. At age 77, Dick succumbed to a long, valiant battle with cancer.

Dick, the brother of a liver transplant recipient, had been President of the TRIO Akron-Canton Chapter since August of 2009.

He was a graduate of Kent State University, served in the Marine Corps and was active in his church and in various service organizations. He was an avid hunter and fisherman.

In a heart-felt tribute to Dick, the chapter newsletter stated:

“He did a wonderful job of conducting TRIO meetings, visiting members in hospitals and nursing homes as long as health permitted. No matter what, he was always available to give us advice. We will always remember him and miss him.”

Claude Brady – TRIO Pioneer



*Nation's Capital TRIO
Chapter 'Founding Father'
Claude Brady is more than
half a century on from his
tongue-twisting diagnosis . . .
and still going strong.*

When Claude Brady was a young bachelor, he knew he wanted to marry a lady who already had children. It was an unusual wish, but Brady was an unusual man. He had a genetic condition that had caused him much suffering, and he was the kind of person who thought ahead—he didn't want to pass his disease on to his biological descendants.

"There was no way I was going to put a child through what I went through," Brady says.

Brady had been a sickly child. Something was wrong with his heart—the doctors could tell from the heart murmur they heard when they examined him, and he could tell because he just didn't feel well. He was often short of breath, his heart pounded hard, he was tired all the time. And the illness seemed to run in the family: his brother and sister both had heart murmurs too, and several family members had died suddenly in childhood or early adulthood from what the family termed the "Brady heart."

But the doctors who first pinpointed cardiac problems were at a loss as to what condition Brady actually had. It wasn't until 1959, when Brady was 22 years old and referred to the Clinical Center of the National Institutes of Health (NIH), that Brady became the first patient in the world to be diagnosed with idiopathic hypertrophic subaortic stenosis. The disease is now known as hypertrophic cardiomyopathy.

"They named it, and it didn't mean anything to me, the name. As time went by, it could roll off my tongue no problem," Brady says. "But these guys, they were excited about this...I didn't know then how excited. They were about to discover a new disease, this was big stuff for them. For me, it was—leave me alone!"

Brady was always optimistic about his prognosis, no matter how poorly he felt. "I told many, many people in 1959: 'My heart's not going to kill me.' I really believed they would come up with something that would help me."

In the process of confirming his groundbreaking diagnosis, Brady's doctors catheterized his heart twice. The second time, Brady went into ventricular fibrillation and the surgeon had to open him up and massage his heart for 17 minutes. Brady is convinced that the squeezing his heart got then made it work better afterwards. A little while after diagnosis, Brady was put on the beta blocker Inderal; the medication helped him enough that he could do his job as a salesman.

Meanwhile, Brady got his wish to have a wife who came with her own children, when he met and married Nancy, who had a daughter and a son from a previous marriage. Nancy was exactly the supportive, level-headed woman Brady had been seeking. They built a happy family life, she working at the Pentagon and he eventually becoming a division manager at Sears. Since they lived close to NIH, Brady could go into the hospital for short stays or experiment with different medications without disrupting their routines too much. For years, his health held up enough that he could keep up with his sales colleagues on the job.

In the 1970's, he started developing symptoms again that slowly worsened with time. He kept working through the decade, until 1983 when he became so symptomatic he had to quit his job at Sears. At home, he worked on his truck, putting a new engine in—and that took him a slow two months as he worked in fits and starts.

Finally, in 1989, it was clear he needed a new heart. When his brother George had gotten his transplant a few years prior, Brady had been very nervous—but he was not nervous now, not for himself. He had seen George's transplant go well, and he just felt his own would work too.

"My brother told me, 'If you wake up from surgery and you can breathe down to your belly button, you know you had a transplant,'" Brady says. "The first thing I did when I woke was take a deep breath." And Claude says "I felt that breath all the way down to my belly button."

The operation had not been easy—the doctors had a difficult time removing his old heart during the Saturday surgery; when he woke on Sunday he was bleeding, and was wheeled back into the operating room. The next time he woke up, it was Thursday.

Yet overall, Brady did well after surgery, with no pain. He has lived with his new heart for 23 years, and is still going strong.

(continued on next page)

Claude Brady -- TRIO Pioneer

(continued from previous page)

When his brother George had undergone his transplant, Brady accompanied George to monthly transplant support group meetings at Johns Hopkins. He learned a great deal from those meetings, and thinks the biggest reason Nancy and he were not concerned about his transplant when the time came was that they'd seen these Johns Hopkins transplant recipients up and about, living good lives.

After his own transplant, Brady and his wife, Nancy, attended a TRIO conference in Pittsburgh and decided to start a TRIO chapter in the Washington DC area. With this decision, they became known as the 'Founding Father' and 'Founding Mother' of the Nation's Capital Area Chapter of TRIO in 1991. The chapter was robust and large, with about 250 members at its most active.

When Nancy died 13 years ago, the NCAC Chapter activities began to slow. Nancy had been the great organizer, setting up events and getting things done; without her, the chapter had no 'shepherd.' Now that some time has passed, Brady would like to get things going again. In December, the chapter met and elected officers, with Trudi Anderson and Mike Garrett serving as Co-presidents, Jim Weaver as Vice President and Claude as Treasurer.

In the meantime, he also runs Transplant Awareness Inc. (www.transplantawareness.org), a nonprofit group that sells T-shirts, pins and other products promoting organ and tissue donation.

Brady advises those facing a transplant to go into it with the mindset it is going to work, and make sure to take medications faithfully afterward. "Half of being a successful recipient is mental—whatever I gotta do, I'm going to do. And then I'm not gonna spend all my time worrying about it. Life is good after a transplant."

Fifty years after his diagnosis, some of his doctors wrote up his case in the American Journal of Cardiology. Even this academic article rings of hope for others with other such conditions: "Claude Brady has taught us a great deal, not only about [the disease] but also the important principle that patients with this sometimes profound hereditary condition can by virtue of their attitudes, perceptions, and fortitude, ultimately prevail against substantial odds."

"One of the things I've been saying is when I reach 75, I'll plan for old age," laughs Brady.

Growing up, Brady was acutely aware of the possibility that his heart might not be beating the

next day. Today, despite some problems such as muscle weakness, his health is "a whole lot better than anyone can ask for. I've done well mentally, that's never been a challenge."

When someone says to me today, 'Boy, you're lucky.' Well, there is one step past *luck*, and that's *blessed*. And I feel I have been blessed."

(Editor's Note: This story was written by Jane Liaw, a professional writer and TRIO Member-at-Large.

See a brief excerpt from Jane's story below. Her full story can be read on www.trioweb.org.)

Jane's Story

Just eight months after our wedding, my husband Taz was hospitalized after routine blood tests indicated something was very wrong.

Though he had a mild case of Crohn's disease, a chronic inflammatory bowel disease, we'd thought he was otherwise healthy. As we waited in his hospital room, though, I thought back to the past few months when Taz had been feeling cold and tired quite often. He wore sweaters when I was warm without them. He had a portable heater he placed next to his desk while he worked, and it was on all the time. He fell asleep watching TV in the evenings all the time.

Taz had a kidney biopsy while hospitalized and the results indicated chronic kidney disease, with little kidney function left. A transplant and/or dialysis would be in Taz's future, sooner rather than later.

The nephrologist we saw for a second opinion, a doctor renowned for his bedside manner and his expertise, confirmed the diagnosis but had encouraging words. His wife had a serious chronic condition, and he told us a little bit about their experience. They'd been married several decades and had teenage children together. They had been living with her illness since soon after they'd met.

Taz is still feeling healthy, working and traveling as usual: so far so good. His sister is entering the home stretch of donor testing and, if all goes well, Taz will have a transplant in the near future. The odds are in our favor, and I don't even consider the possibility that the transplant might not work out.

I don't know what that future will bring. I don't know if soon Taz will not be feeling as good, when his transplant will be, or how well he will do on it. I don't know if we will die old, together, while holding hands on our front porch swing. And if we don't, it would be a shame to waste today worrying about what might happen. All I know is that today, while I have a cheerful and active husband—today is pretty good.

TRIO Advocates Through Washington Roundtable

As one of more than a dozen organizational members of the Washington (Transplant) Roundtable, TRIO continues to join forces with these groups to advocate for important federal legislation that affects our cause. For a complete listing of these groups, see TRIO's website.

Recent activity included meetings with legislative leaders and letters of support for extension of the existing 36-month prescription drug coverage limitation for kidney transplant recipients. More recently, letters offered strong support for federal funding of the organ donation and transplantation programs managed by the Division of Transplantation (DoT) within the Health Resources and Services Administration (HRSA) to retain the existing FY 2012 Level of funding at \$25 million in FY 2013. With today's economic realities, it was considered a better approach to appeal for that existing HRSA funding rather than to appeal for an increase, which was highly unlikely to be granted.

Chapter Champions Still Needed

While a few chapters have nominated their "chapter champions" many still have yet to do so. These local chapter members would serve as the representatives for a distribution list that goes out to them from such focused TRIO initiatives as "Public Policy" and are responsible for being tuned into the activities of that interest group, reporting updates and following up on proposed action plans with their local chapter as well as feeding back chapter support or concerns in that subject area.

Along with public policy, chapter champions are being sought for the Primary Care Physician program, Leadership Summit planning and our Transplant Presentation library. There are no committee meetings to attend, just e-mails to read and act upon, sharing news and updates with your chapter. Are you ready to fill any of these exciting in-the-know "chapter champion" roles? Talk to your chapter president for possible nomination.

Statistics on Heart Transplant

As quoted from a news item on www.trioweb.org: "More than 3100 Americans are waiting now for a new heart and about 330 die each year before one becomes available." See also: www.unos.org and www.optn.transplant.hrsa.gov.

TRIO Youth Circle: Youth Initiative Takes On New Mentor



Looking to grow the TRIO Youth Circle support for our transplant audience of 18 to 30 year olds, board member and transplant social worker, Liz Shore, herself a "youthful" spirit, has accepted the role of mentor to this effort. Together with the existing "YC" leadership team, Liz will be researching ways to engage the growing population of young transplant candidates and recipients who often feel uniquely alone in their medical environments. This is a time when they are facing the world of transplant as young adults with its unique challenges added to those of the many other everyone encounters in facing that age of growth and discovery. Stay tuned for developments in this exciting area of TRIO growth and opportunity. Write to info@trioweb.org if you are interested in getting directly involved in this movement.

Speaking of youth leaders, Mary Wu and her dad, Joseph Wu, were guests of the TRIO Philadelphia Chapter this past month, attending its monthly meeting and sharing their amazing life stories. Their afternoon was spent touring Philadelphia's new Transplant Family House and deep brainstorming discussion of TRIO issues, both youth related and international opportunities. It really is amazing to see and hear what our young transplant recipients are doing with their lives post transplant (Mary has had two kidney transplants) to support others and promote organ donation in so many ways as can be seen in her story featured on the Youth Circle Pages on TRIO's website.

Special congratulations to former TRIO Youth Circle founders/leaders, Holly Werlein and Valen Cover for both being named to Donate Life America's list of "Twelve Women of 2012" - a special new honor given to those "whose lives were transformed by organ donation are helping Donate Life America inspire 20 million people to sign up to be organ and tissue donors this year."

Last Minute NEWS: Former VP Cheney Receives Heart Transplant

By now, most have heard that Dick Cheney, age 71, received a heart transplant after 20 months on the waiting list. Cheney had suffered various heart problems since his first heart attack at age 37. See column on the left to locate statistical information on heart transplant and waiting list.

TRIO Virtual Chapter: Looking for Leaders

With MAL's as a growing and vital part of TRIO, currently representing about 10% of our overall membership, Will Oler and Lou Reardon are looking out for a few members-at-large who might be interested in stepping up to fill proposed "virtual chapter officer" roles. Those leaders would join Will and Lou in developing ways to address the needs of the MAL audience, those TRIO members who are not able to attend face-to-face local chapter meetings due to geographic distance to a local chapter city.

Interested? Write to info@trioweb.org and Will or Lou will get back to you to answer questions or help you engage in this opportunity.

Reminder: MAL's need to maintain their membership with annual dues of \$20 sent to the TRIO national office. If you haven't already done so, mail it in now as your 2012 dues "are due" to continue receiving the benefits of being a TRIO member. And don't forget, MALs can write to info@trioweb.org to get a DVD of any program listed in the Presentation Library on the TRIO website.

TRIO Receives Approval of Continued Partnership with United Airlines

In January, TRIO received confirmation from United Airlines that TRIO's long-standing partnership with the United Airlines Charity Miles Program has been extended through the year of 2012. TRIO is one of only 30 non-profit organizations in the United States selected by United Airlines to participate in this valuable program. TRIO is very appreciative of this opportunity and expresses thanks to United Airlines.

Through TRIO, the United Airlines Charity Miles Program provides frequent flyer seating to transplant recipients, living donors and caregivers who might otherwise not be able to purchase tickets. Due to the length of time required to book seating, the tickets are not available for 'call-in' but are available for round-trip travel for scheduled pre- and post-transplant check-ups and meetings with transplant team staff.

The frequent flyer miles available are donated to TRIO by individuals. To donate miles, go to www.united.com or call 1-800-421-4655.

An information sheet about this program is available on TRIO's website, under "Resources."

TRIO Supports Transplant Community Through UNOS Service

TRIO has a long synergistic working history with UNOS, the organization that oversees the US transplant allocation system and its database of waiting candidates under contract to the government's HRSA. UNOS is unique in many ways, but especially being transparent in its workings supported and accomplished through the efforts of 22 volunteer committees involving hundreds of transplant professionals including patient candidates and transplant recipients.

TRIO is recognized by UNOS as a voting organizational member as well as having our members serving on many of those committees.

Currently, as an example, we know the following TRIO members are serving:

- J.T. Rhodes, UNOS' Patient Operations & Safety Committee
- Merle Zuel, Patient Affairs Committee
- Jim Gleason, Patient Affairs Committee
- George Franklin, Patient Affairs Committee
- Ron Taubman – Pancreas Committee
- Jim Gleason, elected for 3-year term to UNOS Board of Directors (effective June of 2012)

If you know of other TRIO members serving UNOS in this way, please let us know so we can update that list. For detailed information about UNOS committees and how to volunteer your own services as a working committee member, see the UNOS web site at <http://UNOS.org> where committees and their members are listed for easy contact. Even if you are not interested in that involvement, check the TRIO web site for current UNOS news, especially for invitations to offer public comment on issues under discussion.

TRIO Chapter Presidents Hold Quarterly Teleconference

On Monday evening, March 26, TRIO chapter presidents (or representatives) held a quarterly teleconference to share ideas and chapter reports, ask questions and discuss areas of concern. Attending the teleconference, chaired by J.T. Rhodes (Chair of the Chapter Council), were Nancy and Walter Hinkle (Akron-Canton), Suzanne Himes (Greater Cleveland), J.T. Rhodes (Northeast Florida), Jim Gleason (Philadelphia), Mary Alice King (Pittsburgh), Monet Thompson and Steve Okonek (San Francisco Bay), Susan Brown (Southern New Mexico), and Henry David and Ron Taubman (Ventura County/West Valley).

Membership – NEW or 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 \$ _____.

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

Thank You for your tax-deductible donation!

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).

Washington, DC 20037-1233
2100 M St., NW, #170-353
International Organization, Inc.
Transplant Recipients



Lifelines is published quarterly by:

PRESORTED
FIRST CLASS
US POSTAGE
PAID
PERMIT 333
HAGERSTOWN, MD