Valen Cover Joins TRIO’s Board as Transplant’s ‘Youth Advocate’

Valen is a motivated and determined young woman with a mission to educate and inspire. Facing and conquering health issues since the age of five, including a successful kidney transplant at the age of 19, Valen (now 26) lives her life in a positive and giving way, providing hope and inspiration to others.

Since her transplant, Valen’s volunteer work and accomplishments range from founding the South Central PA Chapter of the PKD Foundation to Co-chairing the PKD Foundation Annual Campaign for a Cure that helped to raise more than a million dollars for PKD research. Since 2004 she has been an avid public speaker, raising awareness on local, state and federal levels for issues, funding priorities and awareness campaigns for PKD, while pursuing a full-time career.

In September of 2009, Valen received the annual “Celebration of Life Award” from the Susan P. Byrnes Health Education Center in York, PA. Her spirit is contagious and she has a way of connecting with all age groups. Valen aspired to be a teacher and loves to help and educate youth. Overcoming severe health obstacles at such a young age, helps her relate to the challenges that youth face. As a TRIO Board member, she plans to use her knowledge and first-hand experience to make a difference in the transplant community.

Upon joining TRIO’s Board of Directors, Valen said: “I am grateful to have the opportunity to reach out and bring together the youth in our transplant community, in support of the TRIO mission. I am honored and excited for this new journey and look forward to all the wonderful people I will meet along the way.”

TRIO Awards Four Scholarships for the 2009-2010 Academic Year

With more than 40 excellent applications for 2009-2010 scholarship awards, the Scholarship Committee had a very difficult selection process. TRIO’s Scholarship Committee, chaired by past president Elizabeth Rubin, carefully reviews each application and deliberates based on strict and equally-applied criteria. Other committee members are Susan Pincus, TRIO Board member, Sylvia Leach, Managing Services Director, and Steve Binder, a member of the Northeast Florida Chapter. Any member of TRIO is invited to serve on this Committee.

This year’s Board of Directors Scholarship is awarded in memory of deceased Board member Steven Levitin. The winner of the Board of Director’s scholarship is Colette Jordan, of Lisle, IL. Colette has raised three children and worked two jobs to help finance college educations for her husband and son. (See photo below.)

Colette received a liver transplant in November of 2006. She said: “Determined to honor my second chance at life, after a thirty-year hiatus from school, I enrolled in college.” Colette is receiving a BA in Human Services from the College of DuPage and will be pursuing a Master’s degree at National Lewis University. Colette does public speaking and volunteers with numerous organ transplant organizations, including Students for Organ Donation, Donate Life Illinois, and Gift of Life, and has participated in the U.S. Transplant Games and National Donor Sabbath activities.  

Board of Directors Scholarship Awardee Colette Jordan, of Lisle, IL, with her family.
Hope everyone had a great holiday and that the new year will be healthy, prosperous and happy. I hope that all TRIO members enjoy their gift of life in 2010.

I can’t understand why more recipients don’t join TRIO. The dues are reasonable and the services provided continue to improve. I am very happy to have a great support network of friends I met in TRIO. These are people who understand what I am talking about when we discuss transplant issues. I believe that the friendships made through local TRIO chapters are a super benefit for chapter members. If you live in an area that doesn’t have a TRIO chapter call or email Sylvia Leach, our managing director, and she will discuss what is needed to start a chapter in your area. As a founding member of a TRIO chapter, I am proud and blessed by all the good that is accomplished by our local chapter.

When you look for organizations that stand up for recipients’ rights, the only one that advocates for all recipients is TRIO. TRIO is a voting member of UNOS and many of our members serve on various UNOS committees, giving input on issues affecting recipients. Mike Sosna, our public policy chairman, keeps TRIO up to date on current laws and issues affecting transplantation.

In your transplant journey you usually join a transplant center support group either before or after your transplant. But after the first year, the same items are discussed over and over until you have the answers memorized. TRIO offers great support to new recipients and to those who have had their transplant for more than a year. Any issue that you may have with your transplant, there is someone in your chapter who probably had the same problem or issue and can share information. The social gatherings sponsored by local chapters are a great way to meet new friends who are experiencing the same issues and feelings that you are having.

Chapters are the life blood of TRIO. Their many organ donor awareness projects sign up more donors. The local chapter speakers provide an education on various topics. Now anyone can order a video of talks given at various chapters on many of the important topics in transplantation by talking to your local chapter president. If you are a member at large, call TRIO’s office to order the free video.

Our new board member Valen Cover is working to start a virtual chapter for younger transplant recipients. I have asked several of our local younger chapter members why they aren’t more active and they explain that most TRIO members are older and have different issues than the those issues affecting younger recipients. TRIO hopes that this virtual youth chapter will give the support for issues that face younger recipients. By using Facebook and the internet, various members can communicate their problems and ideas. Your TRIO board sees the younger recipient as an area that needs special attention and hopefully, Valen’s service as a youth advocate will bring this group together.

This will be my last year as president of TRIO’s national Board of Directors. During this new year, I hope that TRIO forms several new chapters, increases its membership and continues being the voice of all transplant recipients.

If you have any ideas on how TRIO can serve you better, let me know!
TRIO Transplant Presentation Library Grows to 10 Titles

_Have you seen the Library yet?_ Last time there were six, now there are ten programs in the growing collection. Our original plan was for one per month, but we are ahead of that goal with programs already produced through March and April delivery!

It is hoped that this video library (housed in a TRIO three ring binder) is being made available at each chapter meeting so that you and any other member can “check out” any of the ever-growing number of very interesting DVD programs for home use. These DVDs will play on any TV-connected DVD player or on your home computer. Check the TRIO web site for the regularly updated index (the last two not yet shipped) that will increase with each monthly addition.

For TRIO members not associated with a local chapter (i.e. a member at large), please contact Sylvia Leach to arrange for use of individual programs. Depending upon demand, we will be making additional copies to satisfy such requests, so there may be some delay in shipment based on demand.

We urge local chapters who have interesting speakers to make arrangements to record those presentations for addition to this library. For general or technical questions contact Jim Gleason at gleasonjim@aol.com. The Presentation Library binder shipped to each chapter president contains the basic recording guidelines and a “Presenter Release Form” for use by the chapters when recording.

This library resource is made possible by generous patient education support grants from Roche and Astellas.

Currently and soon to be released Presentation Library programs include:

- “How to Live to be 100” – Jnanesh Thacker, MD
- “Physician as Transplant Patient”  
  - Rich Kasama, MD
- “Donor Incentives” – Tom Peters, MD
- “Total Artificial Heart – Today and Tomorrow”  
  - Rohinton J. Morris, MD
- “Future Directions in Organ Transplantation”  
  - Howard Eisen, MD
- “Kidney Paired Exchange Program”  
  - Diane James, BSN
- “Transplant Patient Dental Considerations”  
  - Barry Levin, DMD

- “An Overview: Organ Donation and Transplantation Around the World”  
  - John Green, Gift of Life Donor Program
- “Burned But Not Broken: For What Was I Spared?” – Michael Nolte, Burn Survivor and Author
- “Hypnosis as a Medical Aid: Myths & FAQ’s”  
  - Dolores Merrell, MA, MBA, C.H.

Library programs for months 11 and 12 will be released in the spring of 2010.

TRIO Chapter Presidents Hold Quarterly Teleconference

TRIO national sponsored the 2009 fourth quarter Chapter Presidents Teleconference on November 9, 2009. Representatives of seven TRIO chapters attended the meeting: Mike Sosna, President, Long Island Chapter; J.T. Rhodes, President, Northeast Florida Chapter; Steve Herman, acting President, Philadelphia Chapter; Steve Okonek, President, San Francisco Bay Chapter; Rudy Oretga, President, and Susan Brown, Secretary, Southern New Mexico Chapter; Dave Courtney, President, Texas Panhandle Chapter; JoAnne Foley, President Pro Temp, and Ron Taubman, Past President, Ventura County/
TRIO Annual Meeting Held in Conjunction with Quarterly Board Meeting

On October 24, 2009, TRIO held its fourth quarter Board of Directors meeting, in conjunction with the 2009 Annual Meeting, at the Gift of Life Donor Program offices in Philadelphia. The meeting was graciously hosted by the Gift of Life Program and the TRIO Philadelphia Chapter.

Attending the meeting were Board members J.T. Rhodes, President; Elizabeth Rubin, Secretary; Jim Gleason, Treasurer; Board members at large Susan Pincus, Elizabeth Shore and Mark Jackson and ex-officio Board member Sylvia Leach, TRIO’s Managing Services Director.

Also present were Philadelphia chapter members Steve Herman, Faith Carlin and Steve White.

TRIO Scholarship Awards for Year of 2009-2010 (continued from page 1)

TRIO Board of Directors voted to award a scholarship in honor of Helen and Richard DeVos, who have been long-time supporters of TRIO. This year, the scholarship named in honor of Mr. and Mrs. DeVos has been awarded to Sydney Rae Yoder of Bradenton, FL.

Sydney, whose father received a heart transplant in 2006, graduated from high school this past May as valedictorian of her class. While in high school she participated in sports, was assistant editor of her yearbook and maintained membership in the National Honor Society throughout her high school career. She also participated in two church missions, one to a Navajo Reservation in Arizona and one to New Orleans in the aftermath of Katrina. She is now a freshman at the University of Central Florida in Orlando, where she is studying forensic science.

Two TRIO Chapters have provided funding for TRIO Scholarship awards: the Greater Cleveland Chapter and the Northeast Florida Chapter.

The Greater Cleveland Chapter scholarship award was presented to Chelsea Marie Howell of Louisville, KY. Chelsea, who is pursuing a career in pediatric nursing at Bellarmine University, said: “I became more interested in becoming a pediatric nurse after spending 61 days inpatient at Cleveland Clinic due to pancreas problems and surgeries in sixth grade.” Chelsea maintained the number two scholastic ranking in her high school class for four years, despite numerous congenital birth defects. While working part-time, Chelsea has volunteered with patient outings and events at the Home of the Innocents and is a spokesperson for the Make a Wish Foundation.

The TRIO Northeast Florida Chapter scholarship was presented to Jason Adam Lesnick of Wellington, FL. Jason is pursuing an undergraduate degree at the University of Florida in Gainesville, after which he plans to attend medical school. Jason said: “My goal in life is simple: help save as many lives as I can.”

In February of 2007 Jason’s mother donated a kidney to his father. Sadly, his father died of a brain aneurism a few months later.

In addition to receiving numerous honors and awards in sports and service clubs, while in high school Jason maintained membership in the National Honor Society, volunteer as a camp counselor, served as a volunteer with the youth organization at his temple and worked part-time to help with family expenses and save for college.

TRIO Needs Individual and Chapter Support to Maintain Scholarship Awards Program

TRIO has very limited resources from which to award scholarships. One hundred percent of scholarship-designated donations are awarded to students. TRIO national pays all administrative and management costs, while Scholarship Committee members serve voluntarily.

With more than 40 applications this year, it has been most difficult for the Scholarship Committee to eliminate so many worthy applicants. To solve this problem, TRIO seeks the cooperation of its friends, members and chapters.

If your chapter can afford to provide all or part of a $1,000 scholarship in 2010, please help these worthy students. Contact Sylvia Leach for information (email: sleach@trioweb.org).

If you, as an individual, would like to donate to help continue this worthy program, you may do so by contacting TRIO’s national office or you can make a donation online at www.trioweb.org.
In its continuing effort to provide services and opportunities to members, chapters and any interested individual, TRIO shares the following ideas to help you locate resources and information.

TRIO scholarships available
With more than eighty $1,000 scholarships awarded over the past 12 years, TRIO continues to offer academic grants to deserving students who are transplant candidates, recipients, donors or their family members. An application can be downloaded (click on RESOURCES at www.trioweb.org).

These scholarships are generously funded by several TRIO chapters, the Board of Directors, individuals and interested organizations.

Please join us by making your own generous contribution to this TRIO scholarship program.

You can visit the Bulletin Board (at no cost)
Did you know that you can share with others, by topic, or just chat in general, on TRIO’s website Bulletin Board? You can register your comments and visit later to find if anyone has responded.

You do not have to be a member of TRIO to use the sharing element of the Bulletin Board. Just go to www.trioweb.org and click on the link to the Bulletin Board. There you will find varying inputs and opinions and you may share your thoughts, questions and interests. (You do need to register to share your input.)

Why not try it?

Provide a life-saving airline flight
Through TRIO’s partnership with United Airlines, TRIO/UAL offers frequent flyer mileage tickets to recipients and donors who might not otherwise be financially able to transport themselves to transplant centers for life-saving procedures.

These tickets have various restrictions. Information relative to the TRIO/UAL Charity Miles Program can be accessed on www.trioweb.org, under the topic “Resources.”

TRIO is deeply appreciative to United Airlines for their continued support of this program. Remember: when possible, FLY UNITED AIRLINES!

Developing chapters or support groups
TRIO can assist you in developing a support group or starting a TRIO chapter. To inquire, contact info@trioweb.org. By inquiring, you are not committing to start a chapter or support group. Perhaps you would be willing to serve as a contact point in your geographical area to reach out to other transplant recipients, donors or their families.

Provide information and answer questions
Through its various information resources, TRIO attempts to respond to your questions and matters of interest. We do not have a staff of experts. Instead, TRIO relies on volunteer advisors, its Board of Directors and its chapter contacts to respond and provide information.

You may be of service to others if you are willing to participate as a ‘responder’ to questions. Please contact sleach@trioweb.org to offer your services. No expertise is required—just a willingness to try to assist others in seeking answers to their questions.

Website link updates
TRIO seeks to provide you with useable and productive links from its website.

In its constant effort to relay correct information, TRIO website management would like your input. If you find a link that is out of date or not responsive, please let TRIO know so that we may better serve the public on transplant related issues. Contact sleach@trioweb.org with updates, corrections, additions or suggestions for beneficial links.

Publish your opinions and articles
TRIO’s newsletter, Lifelines, accepts articles for consideration if they are of interest in the transplant community. Send a letter of inquiry (not the article) to sleach@trioweb.org.

You will be contacted by a member of the Newsletter Subcommittee relative to the acceptability for publication of your submission.

Your “OPINION PAPER” can also be published on TRIO’s website.

How Can You Help Others?
Donate your United Airlines frequent flyer miles to TRIO’s life-saving ticket program.

Call United Airlines at 1-800-421-4655.

Thank you for helping others!
Personal Reflections of a Transplant Recipient – A Personal Statement by Don Ehnot

The year of 1990 was the most fascinating, interesting, incredible year of my life.

Cardiomyopathy slowly eroded my body over a 2-year period to an emaciated shape. End stage cardiomyopathy concluded with cardiac arrest and code blues. A helicopter rushed me to the Hershey Medical Center. A heart was found in 3 days. The surgery, normally 4-1/2 hours, took 15 hours because of severe bleeding. (I remember little of this). A host of problems followed.

Hershey insisted that I get active aerobically. I resisted because I could not do this before-- I had heart problems all my life. But I listened, albeit with reluctance. Everyday I did a little bit more. I watched my body slowly transform one muscle at a time. My initial reluctance changed to a driving enthusiasm. Energy filled my body with life. At the end of that year I was in the best physical condition of my life. I was reborn during that year. I am now 19 years out and still doing well. My heart has now beaten inside of me for as long as it did inside my donor.

All of us that survived a life saving transplant has a story. How has this experience changed our lives? Our thoughts, before and after the transplant, are different for all of us. Below are mine.

During my declining health and subsequent stay in the hospital I was acutely aware that the people taking care of me were healthy. Healthy people were attending the needs of our society. I was not participating. I watched TV in awe as football players ran and tackled with strength and vitality. Every day I thanked and prayed for the healthy people of the world. Without them the sick would get not get proper care. THANK YOU, HEALTHY PEOPLE!

I realized that if you want to help people you have to be healthy-- physically and mentally. You have to take care of yourself and reserve time for doing things that make you happy. Be a little selfish. Reserve time for the activities that you enjoy—a night out with the girls, a movie, reading... Do not feel selfish or guilty. You are important, too.

You can care for people --your patients, families, and friends --only when you yourself are strong—physically and mentally.

Aerobic exercise is necessary for good physical and mental health. Exercise to get your heart rate and breathing up. It reduces stress, makes your body stronger and increases mental function.

There are no downsides or harmful “side effects”.

Everyone must assume responsibility for his or her own health. You must take charge. One spouse should not follow the other around handing them their medication when its time, remind them of doctor appointments, and so on. A transplant should know the names, and can identify, all the pills they take and when to take them and know why they are taking each pill. Your health is in your own hands and only you can manage it the best.

Be truly thankful of your life even if you have problems. We all have problems. No matter how sick I was during my stays in hospitals I didn’t have to look very far to see people that I would not trade places with. During one hospital stay I saw a women patient on a gurney in a hall. I asked why she was there. The answer “She has no arms or legs. She is blind. She has no family or friends. We can’t afford to keep her anymore. We are trying to find a place for her to stay”. I could go on with more examples. And you think you have problems?

I have learned to “Go with the flow”. Pick your problems and quests carefully. You cannot solve all of the world’s problems. Pick one or two that you can contribute to and make a difference.

Give people their own space. Let them be themselves, with all their thoughts, expressions, and mannerisms. No one is perfect. And demand your own space where you can be yourself with all your traits and idiosyncrasies.

Many transplants have a burning desire to meet their donor families. I have never felt this. I have written three letters to my donor family. The first letter is impossibly difficult as we all can attest to. I never received a reply. This has not bothered me. They have experienced a great personal tragedy. They may still be trying to put this ordeal behind them—if they ever can. My thinking—Can you think of a more beautiful gift than the gift of life from a total stranger? That’s enough for me. Every day I wake up I thank God, my donor, and my donor family.

The best advice I ever received was from a doctor who told me “Listen to your body. It talks to you. It tells you when it’s happy or sad. Pain is a warning that something is wrong. Stop and evaluate it before proceeding further.”

Live life to the fullest. Don’t merely exist. Stop and smell the flowers. Don’t rush through life—you might miss it. Be a participant not an observer.

–Don Ehnot, djehnot@ptd.net
Stenzel Twins Bring Personal Report to San Francisco Bay Chapter

San Francisco Bay Area TRIO members recently heard a first-hand account of the puzzle that is organ transplantation in Japan. Among the richest countries in the world, and one that has contributed greatly to transplant technology, Japan has the lowest organ donation rate in the world. During the first ten months of 2009, the entire country had only five brain-dead donors and 87 post-cardiac-death donors.

Chapter members Ana Stenzel and Isa Stenzel Byrnes recently returned from a nine-city tour of Japan, promoting the Japanese translation of their book “The Power of Two” which details their experiences with cystic fibrosis and subsequent lung transplants. The identical twins are half Japanese and no strangers to the country.

With the prospect of a transplant so dismal in their country, Japanese have gone overseas in hopes of receiving the gift of life. Japan’s TRIO chapter serves primarily to educate people about transplant in the United States, now that much of Western Europe and Australia have closed their waiting lists to them.

The twins explained the ostracism that transplant recipients face in their country, sometimes being looked upon as “living cadavers.” Because there are so few transplants, and the idea of standing out is frowned upon culturally, most recipients keep quiet for fear that the Japanese media will turn their surgeries into a circus.

Isa reflected that the reasons for the lack of acceptance of organ donation in Japan are many. While the country is not particularly religious, Shinto is the only major world religion not supporting organ donation, believing that transplantation goes against the natural order of life. “Ongaishi” (the obligation to return a favor) enters into the mindset as well, as how can one return such an immense gift? The upshot of this scientific-ethical dilemma led to Japan becoming the only nation in the world where individuals can determine the definition of their own death: brain death is death if you choose to be an organ donor, and cardiac death is death for all others.

Living organ donation is more accepted, which obviously limits transplants to kidneys and the occasional liver or lung. Yet, Japanese law forbids living donation from non-relatives. In the case of a deceased donor, the law forbids recipients from meeting donor families.

The twins participated in the 18th Annual Japanese Transplant Games in Fukuoka where 90 athletes, predominantly children who were living recipients, gathered to participate in various sporting events. Because October is organ donation awareness month in Japan, the twins also ran in a recipient relay team at the Green Ribbon Running Festival in Tokyo, the largest transplant awareness event with 4,000 runners.

The twins met several Japanese donor families in their travels. There is no formal recognition for organ donors in the country, so donor families formed a club for mutual support.

There is growing international pressure on Japan, reflected in the WHO Declaration of Istanbul of May 2008, which urged countries and regions to strive to be self-sufficient in organ donation. Yet, with its culture and beliefs so deeply ingrained in the population, efforts to change the Japan national mindset seem almost Herculean.

Transplantation remains a matter of great concern with the Japanese. Most citizens seem willing to receive an organ but are adamantly opposed to signing a donor card. As Mr. Yoshi Nomura, Japan’s TRIO president reflected, “Trying to promote organ donation in Japan is like sprinkling a few drops of water on a desert, and expecting a tree to grow.”

-- Steve Okonek, President, San Francisco Bay Chapter

Contact and Information Points
For Answers to H1N1 Questions
By now, most transplant recipients have read and are aware of the issues surrounding H1N1 and concerns about the available flu shots. To review the latest information, visit the OPTN/UNOS website at: www.UNOS/ORG/newsDetail.asp?id=1292.

As other information becomes available, TRIO will publish informational items on www.trioweb.org under the home page topic “Rx News of TRIO Interest.”
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: __________________________________________________________________________
Phone: _____________________________ Fax: ______________________ email: ______________________________
City: ___________________________________________ ST: ____________________________ ZIP: ______________

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

Recipient Profile (Optional): _______________________________________________________

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

Annual Dues: Member at Large ........... $20.  Make your check payable to and mail to:
Additional Contribution ............... $ _____.  Transplant Recipients International Organization, Inc.
TOTAL enclosed ........ $ _____.  2100 M St., NW, #170-353

Thank You for your tax-deductible donation!  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).