



## **Transplant Recipient International Organization Pittsburgh Chapter August 2012 Newsletter**

### **IN CASE YOU MISSED IT**

The summer edition of the Pennsylvania Caregiver Magazine, published by TRIB TOTAL MEDIA, featured several TRIO members and their transplant story as well as the TRIO Celebration of Life Dinner held on May 18. One of the contributors of the magazine, Gen Lucidi Payne, contacted me in the spring and asked if I would be willing to share my transplant story with her and if I knew others who would do the same. Besides my wife, Chris, and me, Gen also interviewed other TRIO members, including Tom and Donna Meshanko and Robb and Lora Wilson. She not only covered transplant stories, but also included articles regarding some interesting statistics of organ donation, myths versus facts of organ donation and organizations to contact for financial help for recipients and living donors.

The Caregiver Magazine insert was included in both the Pittsburgh Tribune Review and the Greensburg Tribune Review on Saturday, June 16. It was not in the Sunday edition and unfortunately, it is not available for viewing online. Due to the length of the articles, I plan to insert one or two articles into the TRIO newsletter in the upcoming months, courtesy of TRIB TOTAL MEDIA. This month I am using the article titled, “**Transforming Losses into Gains**”. It covers the story of Robb Wilson, a kidney transplant recipient, and his wife, Lora, who altruistically donated one of her kidneys!

### **Transforming Losses into Gains**

By Gen Lucidi Payne

How do you say thanks when your husband, Robb Wilson, receives a new lease on life from a double organ transplant?

If you are his wife Lora, you step up, become a living kidney organ donor—and in the process bond in a mother-daughter type friendship with the woman receiving your kidney.

Then, as a further show of appreciation, you and Robb team up to launch a network of support groups so that others facing similar transplant challenges know they are not alone.

“I was thankful that my transplants were successful,” says Robb. “But, I kept thinking about the donor and that someone had to give their life so that I could live.”

While Lora shared that joy, she was also sensing that, “Somebody Robb didn’t know gave him his life back. I wanted to do the same.”

Theirs is touching tale of how to focus on life’s positives and give back.

Robb Wilson was just 44-years-old when he learned the diabetes complications he had dealt with since he was 13 had caused kidney failure. He needed life-saving kidney/ pancreas transplants. To prepare for the transplants his gall stone had to be removed, further testing his frail medical condition. He then went on dialysis for five months while waiting for organs to become available.

In September of 1999, Robb underwent successful transplant surgery. During the next three months, he was readmitted to the hospital three times to treat infections and other complications before he was back at his job as a data manager at the University of Pittsburgh.

Meanwhile, Lora's gratitude for Robb's transplant evolved into a commitment to become a living kidney donor. She decided to temporarily postpone the surgery, concerned it might worry her mother.

That delay ended when she was participating in the National Transplant Games and heard Ann Lopez, wife of comedian George Lopez, challenge everyone to be donors.

"My mother had passed away. I had two kidneys and was healthy. How could I say no? I felt I was on right path."

Robb wasn't surprised by Lora's decision. "She's that kind of person—brave."

In November, 2006, Lora donated a kidney at UPMC Presbyterian Hospital to the best match on the waiting list. "I never had such peace of mind. I was on a cloud and knew I was doing the right thing."

Two days later, she met the recipient, Dee Iannacone, a New Jersey grandmother whose family has a multi-generational history of kidney disease.

"It's very rewarding being matched with a woman the age of my mother whom I had lost. Dee is now 76 and we keep a close relationship with long telephone talks."

Fortunately, Robb has not experienced rejection since his organs were transplanted almost 13 years ago. But, in 2003 he suffered more diabetes-related complications including a mild stroke and coronary-artery bypass graft surgery. About two years ago, he went on long-term disability due to the cognitive, vision and balance problems caused by multiple blockages in the internal carotid arteries that make it difficult for him to communicate and work with data.

Now 57, Robb remains upbeat in his determination to deal with his medical problems and continue to join Lora in giving back.

That's just what the couple is doing.

While Robb was undergoing his first dialysis treatment, Lora was put in a room to watch a video on dialysis and given more videos to take home. "It was scary—the worst day of my life. I needed someone face-to-face and no one was there. After the transplant, there was also no one to talk to.

The Wilson set out to find support groups. Initially, they joined a group in Greensburg. Then they began working to start support groups closer to their Churchill home. Now there are six Western PA Kidney Support Groups in various locations.

In addition to her job as executive director for the Pittsburgh Bone & Joint Surgeons, Lora helps the support groups with promotional tasks. She was among the original members of the National Kidney Foundation's Living Donor Executive Council and serves on the editorial board for the foundation's e-newsletter.

As his medical condition allows, Robb remains active with the support groups and volunteers with Transplant Recipients International Organization (TRIO) at Family House where he reassures transplant patients and their families.

The Wilsons are looking forward to joining Team Pittsburgh for the National Transplant Games this July in Michigan where Robb will compete in singles and doubles bowling and Lora in the 5K and singles bowling

“I’m not fast, but I continue to run in 5K races to show that being a living donor does not limit one's future physical capabilities,” says Lora who began running at age 50 when the games first allowed living donors to compete.

“I often think about how transplants transform losses into gains--negatives into positives. The family of Robb's donor turned their tragic loss into a gain for someone else. Emerging from the grief I felt after the sudden loss of my mother, I was able to give someone else's mother more time.”



Living donor, Lora Wilson, with kidney recipient, Dee Iannacone at the National Donor Recognition Ceremony

### **TRIO Leadership Summit 2012: Not Just for “Leaders”**

TRIO National is holding a 2012 Leadership Summit in Pittsburgh on Friday, September 28 and Saturday, September 29. The meeting location is at the Center for Organ Recovery & Education (CORE) located at 204 Sigma Drive, RIDC Park, Pittsburgh, PA 15238.

The summit begins with an opening luncheon from 12:00 to 1:00 P.M. on Friday. A variety of workshop sessions follows lunch. At 7:00 on Friday evening is a 25-year anniversary dinner and awards program. Saturday begins with a continental breakfast at 8:00 A.M. and workshops continue up to the conclusion of the summit at 5:00 P.M. The workshop fee is \$50 and the 25-year anniversary dinner and award program fee is \$100. However, the fees are waived for National members. More information of the TRIO 2012 Leadership Summit, such as the agenda of the workshop topics and speakers is on the TRIO website at [www.trioweb.org](http://www.trioweb.org) The registration form to complete and send to TRIO, c/o Sylvia Leach is also available on the TRIO website.

Please inform Mary Alice King, TRIO-Pittsburgh President, if you plan to attend the summit. Please email her at [mak1301@msn.com](mailto:mak1301@msn.com) or by calling the TRIO phone line at 412-647-7461 or toll free at 877-647-3439.

### **2012 TRIO PICNIC**

The TRIO picnic was held on Sunday, August 12, at Cecil Township Park. The beautiful weather added to all the fun and socializing of over 55 members and guests in attendance. Bocce ball was a big hit as well as corn hole toss. And yes, there was even another rendition of the Village People’s “YMCA” sung on the karaoke machine by Paige Quackenbush with help from the entire crowd. Mitch’s Barbeque supplied another delicious meal, followed up by their infamous sundae bar. The only time it was quiet was during BINGO, until there was a winner, of course. Many returned home that day on a full stomach, a smile on their face and maybe a BINGO prize as well. It was a grand day!



### **2012 TRANSPLANT GAMES OF AMERICA**

The 2012 Transplant Games of America took place in Grand Rapids, MI from July 28 – July 31, 2012. Congratulations to all the local participants and medal winners of the Transplant Games of America. To watch a recap of the Closing Ceremonies please go to <http://www.transplantgamesofamerica.org/special-events>



**Members of TEAM PITTSBURGH**

### **NEXT TRIO SUPPORT GROUP MEETING**

TRIO Support Group Meetings are held on the third Sunday of the month, except in the months of August, due to our picnic, and in the month of December, due to our Holiday Party. The meetings begin at 1:30 PM and alternate between Allegheny General Hospital, Snyder Auditorium and UPMC Montefiore Hospital LHAS Auditorium. Flyers are normally sent out before the meetings as well as being posted on the TRIO website. The next TRIO Support Group Meeting is at Allegheny General Hospital, SynderAuditorium at 1:30 P.M. on Sunday, September 16. The speaker and topic is still pending.

### **SAVE THE DATE**

The TRIO Holiday Party will be on Saturday, December 1, 2012 at Calabria's Restaurant. Calabria's is in Castle Shannon on Library Rd/Rt 88 near the intersection with Rt. 51. More details of this fun evening will be forthcoming.

### **CURRENT TRIO-PITTSBURGH BOARD OF DIRECTORS**

Mary Alice King (President), Rudy Molnar (Vice President), Rich Wegrzyn (Treasurer), Paul Armbruster (Secretary), Chris Armbruster, Anna DiPilato, Shannon Flynn, Kathy Jacobs, Carol Foglia, Tom Meshanko, Jo Anne Schwarz, DeeAnne Seeger, Georgene Thomas and Colleen Yost.

## **CURRENT TRIO-PITTSBURGH CHAPTER HONORARY BOARD MEMBERS**

Dr. Kareem Abu-Elmagd, Dr. Thomas Cacciarelli, Dr. Barbara Carpenter, Dr. Robert Kormos, Dr. George Mazariegos, Dr. Dennis McNamara, Dr. Srinivas Murali, Dr. Obaid Shakil Shaikh, Dr. Ron Shapiro, Dr. Thomas Starzl, Susan Stuart, Dr. Henkie Tan, Dr. Ngoc Thai, Dr. Kusum Tom and Dr. Steven Webber.

## **HAPPY AUGUST ANNIVERSARIES**

Joy Jewell: Living Donor in August 1981

Kim Krebs: Kidney, bone marrow and islet cell recipient on 5-25-94. Pancreas recipient on 8-15-00.  
Kidney and pancreas on 12-29-11.

Georgene Thomas: Heart/double lung recipient on 8-31-97. Kidney on 10-21-05.

## **TO CONTACT TRIO-PITTSBURGH CHAPTER:**

Phone: 412-647-7461 or 1-877-647-3439

The mailing address is TRIO Pittsburgh / 3601 Fifth Avenue, Room 601 / Pittsburgh, PA 15213

For more information about TRIO Pittsburgh, visit the website at [www.trio-pittsburgh.org](http://www.trio-pittsburgh.org)

## **HEART SUPPORT GROUP MEETING**

The next scheduled Heart Support Group Meeting is on Saturday, August 25, at Panera Bread on the Boulevard of the Allies. The meeting begins at 12:00 and lasts until 1:30.

For more information, contact Tom Meshanko at [t.meshanko@verizon.net](mailto:t.meshanko@verizon.net) or call 412-351-6704.

## **UPCOMING WESTERN PA KIDNEY SUPPORT GROUP MEETING**

Pediatric Contact: Lori Bible 724-981-0368 [sbible6@msn.com](mailto:sbible6@msn.com)

For more information about kidney disease and support groups visit [www.wpakidneysupport.org](http://www.wpakidneysupport.org)

## **LOCAL SUPPORT GROUPS for LIVER DISEASE**

### GREATER PITTSBURGH PBC (PRIMARY BILIARY CIRRHOSIS) SUPPORT GROUP

Meets on the 2nd Tuesday of each month at Panera Bread – Waterworks Mall – Fox Chapel

For more information contact Ellen Kerber or email at [kerber@kerbers.com](mailto:kerber@kerbers.com)

### LIVING WITH HEPATITIS SUPPORT GROUP

Meets on the 3rd Thursday of each month at

330 South 9th Street, Main Bldg., Room 182 Pittsburgh, PA 15203

For more information contact Jen Warner at 412-535-2670

### WESTMORELAND COUNTY SUPPORT GROUP

Meets every other month on the 3rd Monday (Jan, March, May, July, Sept and Nov) at

Hempfield Church of Christ 144 Hugh Black Rd Greensburg, PA 15601

For more information contact Antonia or Mike Redigan at 724-423-5948 or [antoniaredigan@hotmail.com](mailto:antoniaredigan@hotmail.com)

### CIRRHOSIS ONLINE SUPPORT GROUP

Online cirrhosis support group at [www.mdjunction.com/cirrhosis](http://www.mdjunction.com/cirrhosis)

For more information go to: AMERICAN LIVER FOUNDATION - WESTERN PENNSYLVANIA CHAPTER  
at [www.liverfoundation.org/chapters/westernpa/](http://www.liverfoundation.org/chapters/westernpa/)

**UPCOMING EVENTS:**

**August 27 through September 2, 2012:** ANSYS Mylan Golf Classic at Southpointe Golf Club  
Eleven Nationwide Tour players in the U.S. Open field will participate with others in this local golfing event.  
Once again, Second Chance at Life will be selling tickets at  
<https://www.mylanclassic.com/buytix/SECONDCHANCEATLIFE/>  
100% of ticket sales from this site benefit Second Chance at Life, Pennsylvania Chapter.

**Saturday, September 8,** 3:00 p.m. - 5:00 p.m. Please arrive by 2:30: **STRIKE OUT DIABETES:**  
\$10 donation for 2 hours of bowling at Lokay Lanes, 2147 Mossie Blvd., Monroeville, PA  
This will be a 9-Pin No-Tap Event. Get 9 pins on first ball and it is a STRIKE!  
Advance tickets available. Please call Robb @412-823-5630 or Jack @412-427-2969

**Sunday, September 16,** 1:30 PM: **TRIO Support Group Meeting** at AGH Synder Auditorium

**Friday and Saturday, September 28-29:** TRIO Leadership Summit at CORE  
For more information visit the national TRIO website at [www.TRIOweb.org](http://www.TRIOweb.org)

**Sunday, November 4:** Kidney Walk at the Pittsburgh Zoo & PPG Aquarium  
Check in begins at 7:30 A.M. Walk begins at 9:00 A.M.  
If you would like to walk with Team Pittsburgh, please contact Colleen Yost at [www.colleen@yosts.net](http://www.colleen@yosts.net)  
Or contact Shelly Zomak at [www.zomak@comcast.net](http://www.zomak@comcast.net)

**Saturday, December 1, 2012:** TRIO Holiday Party at Calabria's in Castle Shannon  
More information to come.

**In closing:**

*"Promise me, you will always remember, you're braver than you believe, stronger than you seem and smarter than you think."*

Christopher Robin speaking to Winnie the Pooh

Respectfully submitted by Paul Armbruster, TRIO Pittsburgh Secretary