



Transplant Times

October - November 2015

A newsletter of the Transplant Awareness Organization of Greater Rochester

www.tao-rochester.org | 1.888.664.1463

Inside this issue:

- Kidney Recipient Meets Donor Family (Again) 2**
- Save the Date 3**
- MOHAN Foundation 4**
- Transplant Anniversaries..... 5**
- "Trans-Plants" 7**

Membership Meeting

Guest Speakers / Topic

October 19

Blanket Making for Transplant Patients

November 16

Elizabeth Keirstead RD, CNSD
Transplant Nutrition Specialist
Nutrition Challenges for Transplant Recipients

TAO Meets

**3rd Monday of the Month
6:30 P.M.**

**Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY**

A Message from the President

I'd like to thank Matt for his leadership and dedication to TAO over the past few years. My goals for TAO are similar to our past presidents. These are increased attendance at our meetings, more membership input into the organization and continued growth.

I am honored to serve as your president. For those of you that don't know me, I am the wife of a liver recipient. My husband, Michael, received a deceased donor's liver 13 years ago. I've always said "we had a transplant." I didn't have the actual surgery but was with him and advocating for him every step of the way. Thankfully he continues to live life to the fullest.

Professionally, I am a dental hygienist but stopped practicing full time after Michael's transplant. The past ten years I've been volunteering at Strong, the Rochester Eye and Tissue Bank, Finger Lakes Donor Recovery Network and TAO. Currently I am employed at Strong in the Friends of Strong.

Did you know that TAO is the only organ & tissue transplant support group serving the Greater Rochester area and surrounding counties? Have you been looking for a way to become involved in TAO? We have many opportunities if you can't attend meetings; attending a euchre tournament or shopping on Amazon.com, contributing to ROC the Day, gift wrapping at Barnes & Noble to name a few. Feel free to contact us with



any ideas or needs that you want to share. This is your organization, you make it what it is! Tell your story in the Transplant Times, suggest a speaker for our monthly meeting, we welcome your input.

With the holidays approaching I'd like to challenge each and every one of you to become an advocate for organ, eye and tissue donation and to actively encourage your friends, relatives, co-workers and neighbors to enroll in the donor registry. Give the gift of life!

Debbie Gendrzeski

Visit & like our Facebook Page

www.facebook.com/TaoOfRochester



SHARE IT WITH OTHERS

Ask your friends to like us!

TAO Providing support, understanding, education & resources . . .

Kidney Recipient Meets Donor Family (Again)

by Penny Sayles

In 1998, I received a life-saving kidney transplant at the U of R. I was 36 years old, a wife, mother, and full-time teacher who had been doing dialysis for 6 years prior to the transplant. While at a dialysis treatment, my nurse approached me as I was completing my treatment, and whispered to me, "Are you ready?" Somehow, I knew exactly what she meant.

My new kidney was arriving from Northwest Pacific Hospital on the west coast early the next day. A few doctors came in for a last-minute examination, and I could hear only bits of pieces of information about my donor. I felt extremely saddened and a rush of excitement both at the same time. I knew someone else's loss was a chance for a healthy, normal life. It was a very strange, unusual feeling.

Immediately after the transplant, I wrote my donor family a letter of gratitude and provided some information about myself and was hoping to hear back from them, especially to learn more about my donor, yet I did not. Five years later, as my family and I were to travel to the west coast, I wrote my donor family again, hoping they would be ready to meet me, and the day before I was to leave, I received a phone call from a very kind, bubbly voice saying that her name was Angie, the wife of Kevin, my kidney donor. I almost fainted. As we continued to talk, I learned a lot about Kevin, a 28 year-old man who was a father of 2 small boys, ages 5 and 3 at the time of his death; he was a true cowboy; master mechanic and carpenter, a real man's man, who died due to accident at his workplace at the National Guard. He was born, lived, and died in Great Falls, Montana. Although I was not able to meet my donor family during that trip for logistical reasons on both our parts, Angie sent me Kevin's picture, and we instant messaged each other constantly after that. We had long phone calls every month, and within a year, I traveled there to meet her and their children. I spent four wonderful days with a family that I genuinely felt that I knew my whole life. It was comfortable and easy, especially since they, and his extended family and friends, embraced my being there. Three years later, Angie and the boys, Kyle and Kole, came to Rochester for

a week to meet my family and friends; and again, it seemed so natural and easy. As her boys grew older, their lives were very busy, so travel was very limited, but we remained in touch with our Facebook and monthly phone calls, and remaining in each other's lives every step of the way.

This past May, I received a wedding invitation to Kyle's wedding in Montana. It was sent as a courtesy, but for me, it was a no-brainer; I would definitely attend. I booked my flight that very day. During my flight there, I did not know what to expect upon my arrival...would the boys (men, now) still remember me in the same way, would I still connect with them and Angie like we had since I last saw them in 2006? Well, it was like time had stood still! The boys were grown up, handsome, successful, and the dialog we shared was like it was yesterday. I was able to meet more of Kevin's friends and extended family at the wedding, and they were so kind and welcoming to me. I spent a day with his parents, who have always remained in touch with me, and like with Angie and boys, there is this special connection that is so effortless. I was able to share with their family, a very special day, and it felt so right and comfortable; to meet my donor family again and of course, will not be the last.



L to R Kyle, Penny and Kole

community events

Save the Date . . .

- **Tuesday, December 1**
ROC The Day
www.roctheday.org/
TransplantAwarenessOrganization
- **Saturday, December 19**
Gift Wrapping @ Barnes & Noble
Pittsford Plaza
 10:00 am to 10:00 pm - 2 hour shifts
 Contact Bev Shank @ (585) 313-8271

United Network for Organ Sharing

Candidates listed as of 10/2/2015

101,189	Kidney
15,080	Liver
4,180	Heart
1,954	Kidney/Pancreas
1,527	Lung
1,044	Pancreas
263	Intestine
48	Heart/Lung

122,403

TOTAL

Total may be less than sums due to patients in multiple categories

www.unos.org

transplant

Support Group Meetings

"Open Airways" - Lung Gathering Group

Thursday, October 15 @ 12 noon

Jeremiah's - 2164 Fairport Nine Mile Point Rd. Penfield

Thursday, November 19 @ 12 noon

Corner Bakery Café - 3300 Monroe Ave. Pittsford

Heart Transplant/VAD Support Group

Thursday, November 12 @ 6:30 pm

Bethany Barney, RD Heart Failure, Transplant, VAD Dietician

Thursday December 10 @ 6:30 pm

Heart Transplant, VAD Holiday Party - Details to follow

* All Heart Transplant/VAD Meetings are held at the 7th floor conference room near the 7-3400 Corridor unless otherwise indicated.

Tuesday, December 1

ROC

THE · DAY

Choose. Give. Matter.

Transplant Times

Submission Deadline

**For December 2015 January 2016 issue:
November 2, 2015**

Articles /ideas email to:

auggieday@aol.com or send by mail to:

TAO, PO Box 23552, Rochester, NY 14692-3552

MOHAN Foundation

by Dr. Anirban Bose, MD

For 16-year-old Sandeep, an Indian teenager in Bangalore, life was nothing like normal. At a time when most of his peers were busy with high school coursework and nursing secret crushes, Sandeep faced the nerve-racking prospect of his own mortality after he was diagnosed with severe heart failure. He had less than three months to live unless he got a heart transplant. Someone had to die for him to live.

But transplants don't happen automatically when someone dies. A whole series of events have to be orchestrated to confirm that the dead person's organs are healthy enough to be transplanted: that his or her family is willing to donate: that the grieving family's religious and spiritual needs are met: that trained grief counselors offer information about organ donation in a non-judgmental way: that the patient on the transplant waiting list is notified immediately: that doctors are prepared to walk into the operating room at any time of day or night when such an event occurs: that this altruistic process is not corrupted by money or favoritism: that the public is sensitized to the true nature of this process: that this process perpetuates and spreads through society and that awareness amongst the general public reaches a level of acceptance that a majority come forward to donate their organs after death. In the US the United Network of Organ Sharing (UNOS) carries out these tasks. But in India, in the absence of a national program like UNOS, thousands of patients die every year awaiting an organ transplant. Others buy organs from people who have been tricked into "donating" their kidneys, keeping alive the business of organ trafficking.

MOHAN Foundation

Founded in 1997 by Dr. Sunil Shroff, MOHAN (Multi Organ Harvesting Aid Network) Foundation is a non-governmental organization that leads this mission to facilitate **deceased organ donation** in India.

Since their inception they have facilitated over 5000 organ transplants including hearts, kidneys and livers. Their trained grief counselors meet with the dead person's family to counsel them about donating their loved one's organs. They set the ball rolling on the process of notifying doctors to harvest the organs, notifying the hospital of organ availability, notifying the patient awaiting an organ that their long wait is over. They educate the public, increase awareness about organ donation, and work with the government for legislation to promote organ donation. They ensure that this altruistic process is free, fair and transparent and not corrupted by money or favoritism. They do not pay anything to the organ donor family, nor do they receive any monetary benefit from the recipients. All their services are provided free of charge. They survive on the philanthropy of the community.

The Impact

The impact of the foundation's work is felt in stories like that of Samagna, a medical student, who saved the lives of four others when she died of a stroke at age 18. Or that of a construction worker from a small village in India who donated his only son's organs to save five other lives when approached by the trained counselors of the MOHAN foundation. Or that of Lalitha Raghuram, country director of MOHAN foundation, who not only talks the talk but has walked the walk when her 19-year-old son was struck in a road accident and declared brain dead. All of them have given so much at their moment of greatest grief because they see the nobility of the cause. And it is decisions like these that impact the lives of people like Sandeep inside whom beats the heart of a 25 year old, making Sandeep now strive for all those things that any other teenager would.

Should you require more information about their work, please visit their website at www.mohanfoundation.org

Transplant Anniversaries

Michelle Halloran	Kidney	October	1997
Bernard Blocchi	Liver	October	1996
Claudia Ciresi	Liver	October	1994
Dave Johnson	Liver	October	2000
Dennis Kovel	Kidney	October	2001
Louis Latorre	Liver	October	2007
Bob Legge	Kidney	October	2009
Thomas Murphy	Liver	October	2009
Keith Oliver	Liver	October	2002
Carol Pfuntner	Kidney	October	2001
Carrie Rodriguez	Kidney/Pancreas	October	2005
Marsi Rohde	Kidney	October	2013
Mary Stein	Liver	October	2005
Bob Munn	Liver	November	2010
Jerry Runion	Kidney	November	1994
Kenneth Andrus	Liver	November	2008
Donna Crosby	Liver	November	2003
Peter Davis	Liver	November	1996
Daniel Phillips	Liver	November	2009
Michael Stelljes	Liver	November	2001
Mike Swete	Liver	November	1995
Eric Wright	Lung (2)	November	2006

Welcome New Members

Kirk Wilson
Bethany Gee

Contributions

Bev Shank
Richard Forbes

In Memory of:

Sandy McNitt
Dave and Rosemary McNitt

Jane Hogestyn
Shirley Hogestyn

In honor of:

G. Murray Thomas
Jeananne Thomas

Board of Directors & Officers

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Gretchen Collins

Treasurer

Karen Gledhill

Matt Felo

Geoff Foley

Secretary

Bev Shank

Karen Guarino

Bonnie Haefner

Membership

Norman Breen

Amy James

Judy Munn

Janice Odenbach

Wishes of Wellness

Our healing thoughts and prayers go out to:

Bonnie Haefner

Cindy DeShane

Laurie Packard

Norm Breen



Our Sympathies

The Family of Jane Hogestyn

**Norm Breen on the death of his brother
Bill Breen**

Pink PanTee Open Benefits Patient Transplant Fund

Monday, August 3 at Victor Hills Golf Club, TAO members Linda Barnard, Marlene Begy, Debbie Yendrzkeski, and Karen Guarino golfed in the Pink PanTee Open to raise funds for the patient fund at URM Strong Hospital.

L to R: Marlene Begy and Linda Barnard



Tops Never Stops

Tops cards help TAO raise money.

The Tops Gift Card Program allows our nonprofit organization to earn a 5% return by selling Tops Cards. Contact Bonnie Haefner at (585) 391-3555

The more we sell, the more we earn.
The cards are available in \$25s, \$50s and \$100s.

TAO Communication

TAO keeps you informed and updated by e-mail on important organizational news, upcoming events, and other transplant-related issues that may impact membership.

Please look for these e-mail notices. The subject line will read: **TAO Communication.**

Also, if there are any changes or cancellations that need to be communicated to you regarding a meeting or event, we can keep you informed and up to the minute.

Please include your e-mail address when renewing your membership dues so that you may be able to receive this information. These are held strictly confidential and are not shared!

Shopping at Amazon?

TAO can benefit from your purchases. Go to

www.tao-rochester.org

and click on the Amazon widget

to do your shopping!

"Trans-Plants"

by Lori Laine

What a year this has been, with four Donate Life events in Orleans County! The first one was held in April at the Orleans County Motor vehicle department. The county was kind enough to let me set up an information table for the day. It was wonderful speaking to many people as to the importance of signing up on the organ donor registry, I was so pleased with the warm reception I received and the people who signed up that day!

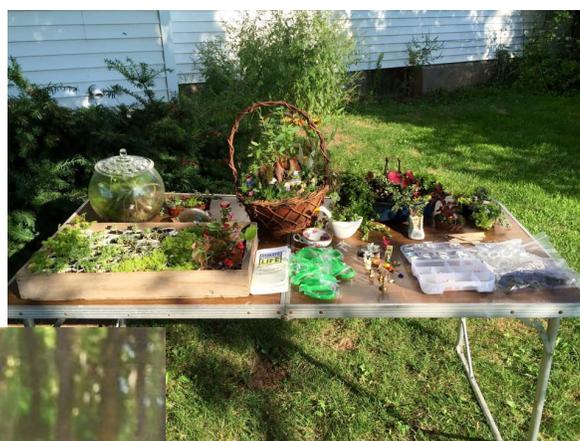
Next was the indoor yard sale and basket raffle to benefit Donate Life and TAO. This was a huge success! Many people of our community came out to show their support and signed up to become organ donors! We had over 30 vendors at the show and over 75 baskets that were raffled off to benefit Donate Life and TAO. The best part of my day was when the high school volunteer asked me what is Donate Life? After explaining it to her she said she and her family will all sign an Organ Donor card! Education is the key!!

The next event was the Donate Life "Trans-plant" sale at the Albion Strawberry Festival. This was the second year for this event. I made terrariums and fairy gardens available for sale with the proceeds going to Donate Life; it is such a great time talking to folks about organ, eye and tissue donation and signing up new donors!

Last one for the year is the Donate Life table at the Christmas Antique, Collectable and Artisan show held at the Orleans county fairgrounds. The shows promoters approached me and offered a spot (which they donated) to have an information table set up for Donate Life! So I made a few fairy baskets to raffle off, grabbed my information suit case and off I went, I will never turn down an offer to spread the word on the importance of being an Organ Donor!

But the best part of this whole year was celebrating my husband's first year anniversary of his liver transplant in July. Every day we thank God and his donor family for allowing my husband to stay with us!!

Many people ask me why I am so involved with Donate Life, now that my husband already had his transplant. My answer is that if people would have been this involved 20 years ago in NY State perhaps now no one would have to be on a transplant list for three years as my husband was. By educating the public the number of people signing up on the Organ Donor Registry is rising! If you think there isn't anything you can do though help spread the word about Donate Life you are wrong. We can all be the face and voice for Organ, Eye and Tissue Donation. I am just one person, one who wants to make a difference, one who hates the wait, and prays that every day that wait will get shorten.





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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

DUES: \$20 Family / Individual \$100 Business / Organization New Member Renewal Date unable to make dues payment at this time

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to: TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) Spouse/companion

Address City State Zip

Phone () E-mail

- Candidate Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants Hospital

Date(s) Organ(s)/Tissue(s)

Check here if you do not wish your transplant anniversary date to be published in the Transplant Times.