



# Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

Providing support, understanding, education and resources for transplant recipients, candidates and their families.

March / April 2012

[www.tao-rochester.org](http://www.tao-rochester.org)

**1.888.664.1463**

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## Membership Meeting Guest Speakers / Topics

**March 19, 2012**

**Euchre Tournament  
Elks Club - Webster  
(Details inside)**

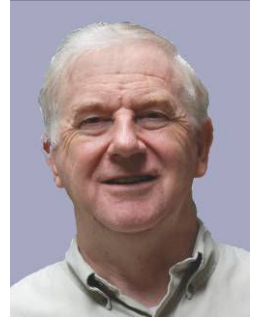
**April 16, 2012**

**What's New in Organ & Tissue Donation  
Update from FLDRN & RETB**

## TAO Meets

**3rd Monday of the Month  
Christ Episcopal Church  
Fellowship Room  
36 South Main Street  
Pittsford, NY**

## A Message from the President



Those of us who are organ recipients know that our transplants represent a miracle of modern medicine, and are truly the Gift of Life. Elsewhere in this newsletter is the story of a young girl who, in the past few months, received the Gift of Life. What is especially noteworthy about her story is that her surgery involved the transplantation of six organs simultaneously, an extraordinary achievement!

Medical science continues to progress at a rapid pace and we can be sure that a few decades from now organ transplantation will have advanced far beyond today's methodologies. Efforts are already underway exploring approaches to eliminate the use of immunosuppressants, drugs that have many undesirable long term side effects for organ recipients. It also seems likely that stem cell research will yield ways in which normal function of some diseased organs can be restored. Furthermore, stem cell technology perhaps holds the promise of "growing" entire organs that are compatible with the host into which they are transplanted. I think we can safely assume that human ingenuity is such that few health problems will be beyond the reach of medical science in the long term.

While those of us who are already organ recipients will most likely not benefit from such dramatic new developments in transplantation, many of us are anxious to keep abreast of the incremental improvements that are being made in transplantation, immunosuppressant medications, and the evolving recommendations on what we can best

do to stay healthy as organ recipients. With this in mind, I am delighted to announce that TAO is privileged to add to its board Chris Barry, MD, PhD, a transplant surgeon at the University of Rochester Medical Center. This addition to the board will give TAO an even closer connection with the medical community involved in transplantation here in Rochester. This will help reinforce our efforts to support the transplant community in Rochester in a number of ways including the selection of speakers for our membership meetings, and through the transplant-related information we are able to provide to the membership via communications such as this newsletter. Beyond his URMC responsibilities, Dr. Barry is heavily involved in bLifeNY, a college-based program devoted to increasing awareness of the need for organ and tissue donation. More information about bLifeNY can be found at [www.blifeny.org](http://www.blifeny.org). In the meantime, we are very grateful to Dr. Barry for agreeing to join the TAO board.

Please note that our regular membership meeting in March is being replaced by a Euchre Tournament at the Elks Club in Webster to raise funds for TAO. Polish up your Euchre skills! We look forward to seeing you there on March 19.

*Geoff Foley*

## A Perfect Match - In More Ways Than One

February 8 will be one year since I gave my kidney to my sister-in-law. I now am reflecting on all the tests and blood samples leading up to the surgery. Talks with family, nurses and my surgeon Doctor Marroquin all helping me to make a decision that would save my sister-in-law's life. At the same time all looking out for my well being too. I won't tell you that removing my kidney didn't HURT. Because it did. And there was the down time for my body to heal. But after a years time. Seeing the remarkable recover my sister-in-law has accomplished with the help from the staff at Strong Hospital, watching her return to work and seeing her enjoying life again with my brother and their son.... Has brought great joy to my life!!! I have never regretted the decision to donate my kidney. And I encourage others to mark their driver's license as a organ donor.

- Kathy Adams

*By Mike Cutillo. Finger Lakes Times*

At any time in the United States, it's said that 87,000 people are waiting for kidney transplants. And the average wait is about five years, usually to receive a kidney from a deceased donor.

Barb Adams would be on that list right now if not for the overwhelming generosity and awe-inspiring compassion of her sister-in-law, Kathy Adams.

On Feb. 8 - in a pair of six-hour operations at Rochester's Strong Memorial Hospital - first Kathy had one of two healthy kidneys removed from her body and then Barb had it transplanted into hers. Now they share not only a last name - Barb is married to Kathy's brother Neil - but also body parts, to say nothing of a kindred spirit toward live organ donation.

"My doctor came to me before we went into the surgery and said, 'You're saving a life today,'" Kathy said. "And then the nurse says, 'You're giving Barb a new birthday. This is her new birthday.'"

Added Barb: "I'm just very, very grateful and, you know, very surprised that she really wanted to do this so badly."

Both women are recovering nicely at home.

Kathy, a dairy farmer in Phelps, hopes to be ready to do the spring planting in April. Barb, who lives in Newark, is hoping to be back at her job as a teacher for the blind and visually impaired for Wayne Finger Lakes BOCES within a few months. There were some initial signs that her body was rejecting the new organ, but currently everything is fine, and Barb says she is getting better every day.

She was first diagnosed with kidney disease about 10 years ago; technically, it was something called glomerulonephritis, an inflammation of both kidneys often caused by a strep infection. It had been in remission from about 2003 until last February but then advanced to the

point where she had to have dialysis four times a day at home, which is when doctors determined she needed a transplant.

That's when Kathy stepped in and decided she would start being tested to determine if she could be a donor - a process that included dozens and dozens of vials of blood, a stress test, an ultrasound, CAT scans and more. "I couldn't believe everything they tested," said Kathy who was found to be a blood and tissue match for her sister-in-law.

Barb's husband also was tested, and he, too, proved to be a match. The discussion then turned into who would be the donor.

"They had a little debate between the two of them, and I think for my son's sake, they kind of decided Kathy would do it," Barb said.

Of course, for 9-year-old Ben, even that was a difficult option.

"I think he was worried because she is one of his favorite people, so he was worried about her and me," Barb said. "But he seems OK, now."

In fact, everyone seems OK, and part of that also has to be attributed to Kathy's sticktoitiveness. See, once it was judged that all the pieces would fit, doctors told the women that the surgeries - might - happen by Easter.

That wasn't fast enough for Kathy, who needed to be recovered and able to get afield by spring.

"She kind of stirred the pot, and the doctor said that's really what got us in so quickly," Barb said. "But he said that's the way it should be."

Kathy said she called Strong so often inquiring about the procedure that "they knew it was me as soon as they answered the phone."

Now that the procedure is over and both women are on their roads to recovery, they also are big-time advocates for live donor donation.

"I would encourage people to explore it," Barb said. "They really have to think about it, but at least explore it. It's amazing to give people their life back. I think there are rewards in that."

Those rewards certainly have touched Kathy's heart.

"It makes you feel good inside to know that you helped her out, you helped the whole family out," said Kathy, noting that one of the get-well cards she received came from a friend of Barb's.

"It's the one I'll always remember," she said. "I didn't even know her, but it said, 'Thank you for giving me more time with my friend.'"



Barb (L) and Kathy Adams

# Euchre Tournament

to benefit Transplant Awareness Organization



**Monday . March 19**

Webster-Fairport Elks Lodge  
1066 Jackson Road  
Webster . NY . 14580

Doors open @ 6 p.m.

Games begin @ 6:30 p.m.

\$20 / person -  
includes 8 games & food

Cash bar



For pre-sale tickets call

**377-6028**

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### Join a Committee

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Membership, Awareness  
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## Shopping at Amazon?

TAO can benefit from your purchases. Simply go to [www.tao-rochester.org](http://www.tao-rochester.org) and click on the Amazon widget and do your shopping!



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

## Our Sympathies To...

To Mary Morey on the recent passing of her husband Larry.

## United Network for Organ Sharing

*Candidates listed as of 2/6/2012*

<b>90,787</b>	<b>Kidney</b>
<b>16,040</b>	<b>Liver</b>
<b>3,123</b>	<b>Heart</b>
<b>2,121</b>	<b>Kidney/Pancreas</b>
<b>1,669</b>	<b>Lung</b>
<b>1,312</b>	<b>Pancreas</b>
<b>280</b>	<b>Intestine</b>
<b>60</b>	<b>Heart/Lung</b>

**112,904** **TOTAL**

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

[www.unos.org](http://www.unos.org)

## Maine girl bouncing back after 6-organ transplant

CLARKE CANFIELD | *Associated Press* – Fri, Feb 3, 2012

HOLLIS, Maine (AP) — A 9-year-old Maine girl is home from a Boston hospital healthy, active and with high hopes - and a new stomach, liver, spleen, small intestine, pancreas, and part of an esophagus to replace the ones that were being choked by a huge tumor.

It's believed to be the first-ever transplant of an esophagus and the largest number of organs transplanted at one time in New England.

Spunky and bright-eyed as she scampered around her family's farmhouse outside Portland, Alannah Shevenell said Thursday that she's glad to be feeling well again and able to go sledding, make a snowman, work on her scrapbooks and give her grandmother a little good-humored sass.

The best part, though? "Being home," she said. "Just being home."

It was 2008 when Alannah, then 5, began running a fever and losing weight while her belly swelled. Doctors discovered the tumor that year and twice attempted to remove it, as it made its way like octopus legs from organ to organ. But it was difficult to access what turned out to be a rare form of sarcoma, said Debi Skolas, Alannah's grandmother, and chemotherapy didn't do the trick, either.

All the time, the growth - known as an inflammatory myofibroblastic tumor - continued to grow in her abdomen, causing pain, making it hard to eat and swelling her up with fluid. Surgery was the last resort to save her life, and Alannah spent more than a year on a waiting list for the organs, said Dr. Heung Bae Kim, the lead surgeon on the procedure at Children's Hospital Boston.

The family was told there was a 50 percent chance Alannah wouldn't survive the procedure. But without it, she had no chance whatsoever.

Things were more tense than celebratory in October when doctors prepared to remove the growth and the organs in one fell swoop and replace them with organs transplanted in one tangled piece from another child of similar size.

The hardest part was taking out her organs and the tumor, Kim said, calling it a difficult operation with lots of blood loss.

"It's probably one of the most extensive tumor removals ever done," the surgeon said.

Dr. Allan Kirk, professor of surgery at Emory University in Atlanta and the editor-in-chief of *The American Journal of Transplantation*, said no other esophageal transplant has been reported in medical literature.

After the surgery, Alannah spent three more months at the hospital, with her grandmother sleeping every night in a lounge chair by her bed. She battled infections and complications from the surgery before finally being given the OK to leave.

She arrived back home Wednesday in the 192-year-old

house on a country road where she lives with her grandmother and grandfather, Jamie Skolas, in Hollis, a town of 4,500 residents about 20 miles west of Portland. But just because she's home doesn't mean she's out of the woods. Alannah has to take nine medications each day, some two, three or four times. Her grandparents have to precisely measure what goes in and comes out of her body, and check her blood sugar.

She has an ostomy pouch and feeding tube attached to her for nutrition as she slowly gets used to eating again. Scars from her surgeries look like a roadmap on her stomach. A tutor comes to the home 20 hours a week for her schooling.

Her immune system is so weak that she can't go to places with large numbers of other people, such as school, church or a mall. She can't eat raw vegetables or fruits unless they have thick skins because of concerns over germs, and she'll never be able to swim in a lake because of the bacteria. The Skolases installed ultraviolet lights in their heating ducts to kill mold, mildew and bacteria that might sicken Alannah.

Alannah is aware of her limitations and what she's been through. "Don't even ask," she says when the subject of the medical costs, which have been covered by MaineCare - Maine's version of Medicaid - come up.

She's talkative and enjoys bantering with her grandparents.

"Grammy, you're not always right," she said to end a conversation.

The Skolases, who took Alannah in several years ago but declined to discuss the whereabouts of her parents, have made sacrifices for her through the years. Their handcrafted furniture business has suffered, with Debi devoting her time to care for Alannah, and the couple has dipped into retirement savings to make ends meet.

Friends have organized a fundraiser to help raise money to offset the costs.

More than anything, though, the family is thankful for the girl's second chance at life and to the family that went through the pain of losing a child and before deciding to donate the organs to help Alannah.

"That was a courageous decision," Debi Skolas said. "I still cry when I think about it."

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## Transplant Times

### Submission Deadline

**For May/June 2012 issue:  
Monday, April 2, 2012**

**Articles /ideas email to:  
auggieday@aol.com or send by mail to:  
TAO, PO Box 23552, Rochester, NY 14692-3552**

## Angel Flight Northeast

Founded in 1996, Angel Flight Northeast is a 501(c)3 non-profit organization providing free air transportation to patients and their families needing to travel for medical treatment whose financial resources would not otherwise enable them to receive care. We have over 1,000 volunteer pilots who donate their planes, fuel and time to support our organization's mission. Angel Flight Northeast also provides transportation for organs, patients waiting for organ transplant and patients who may live in areas without access to commercial airplanes. We also provide compassion flights to those supporting family members in need of medical care and for other humanitarian and compelling reasons. AFNE flies patients for free as long and as often as they need to travel, with no limit on the number of flights provided. Angel Flight Northeast principally serves a nine-state region comprised of MA, NH, ME, RI, VT, CT, NY, NJ and PA. As for the process, an individual or family who could benefit from our services should call us at 800-549-9980. We don't require pre-approval only that those who ask for our help truly require it.

The process is fairly simple – our flight coordinators will conduct a patient/passenger intake which takes between 20 to 30 minutes. The passenger(s) must be medically stable and able to climb in and out of a small general aviation aircraft. Since our pilots are volunteers and provide their services as their schedules allow, we appreciate as much advance notice as possible. This enables our flight coordinator to provide the best service possible and ensure the time needed to coordinate with them and arrange the flight.

To learn more about Angel Flight Northeast, contact us at 800-549-9980 or visit [www.angelflightne.org](http://www.angelflightne.org).



## Transplant Anniversaries

CYNTHIA BOYER-GREEN	KIDNEY	March	1996
RITA CALLAGHAN	LIVER	March	2001
JANA CURRIE	LUNGS (2)	March	2008
KAREN GLEDHILL	KIDNEY	March	2008
ROBERT HADSELL	LIVER	March	1997
THOMAS LOUER	LIVER	March	2004
PAULA MCKAY	KIDNEY	March	1995
JAN SHARP	KIDNEY	March	2005
DENNIS WITTMAN	LIVER	March	2004
WAYNE DICKINSON	KIDNEY	April	2008
JAMES GRACZYK	LIVER	April	2002
MICHELLE HALLORAN	KIDNEY	April	2010
CHUCK LUNDEEN	LIVER	April	2008
SUSAN MAGLISCO	LIVER	April	2010
SHARON MOONEY	KIDNEY	April	2010
GERALD MUTO	KIDNEY	April	2010
BERNIE PIERCE	LUNGS (2)	April	2011
PENNY SAYLES	KIDNEY	April	1998
MERRILLAN THOMAS	KIDNEY	April	2010
G. MURRAY THOMAS	KIDNEY	April	2010
ASYA ZARKHI	KIDNEY	April	2003
GINGER ZIMMERMAN	HEART	April	1998

## Contributions

*We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.*

*If we omitted you, please let us know so that we may post in the next issue. **THANK YOU.***

Rob & Carole Kochik

*In memory of Patricia Ann Terra:*

Judith Cushman

Reuben Ortenberg

Ann Marie Dinino

William & Diane Howie Jr.

Marie Carole

*In memory of Stacia Davies-Vogt:*

Dave & Joyce Davies

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## Holiday / Recognition Dinner

TAO celebrated its 10 year anniversary during the Holiday Recognition Dinner at the Brook House Restaurant on Saturday, January 14, the coldest, snowiest day that we've had so far this winter, TAO members were warmed by a yummy buffet dinner. The history of TAO was relayed, thanks to Karen Guarino. Members browsed through two photo albums that showed the founding fathers of our organization. Geoff Foley, TAO president, welcomed everyone and introduced new members that were present.



Bonnie Haefner



Dr. Barry



(L) Linda Barnard (R) Karen Gledhill



(L) Richard and Jeff Orrvick



Linda and Glen Cone

## Save The Date . . .

### Rochester River Run/Walk 5K set for April 22

Individuals and teams are invited to participate in the 11th annual Friends of Strong Rochester River Run/Walk 5K, Sunday, April 22, at the Roundhouse Shelter at Genesee Valley Park. The race will begin at 10 a.m. As more patients receive organ transplants each year at Strong Memorial Hospital, including heart, liver pancreas and kidney transplant – many need assistance as they await operations as well as after transplant. Former patients also return to Rochester for follow-up medical care, swelling the ranks of individuals in need of help. All money raised through the Rochester River Run/Walk goes to support transplant patients.

Pre-registration deadline is 4 p.m., April 20. Pre-registration fee for the River Run/Walk 5K is \$25 per person. On race day the fee will increase to \$30.

Pre-registration forms and race packets will be available at Medved Running and Walking Outfitters, 3400 Monroe Avenue, Rochester, NY 14618-4725, (585) 248-3420. Registration forms will also be available at Friends of Strong.

For more information or to register, call Friends of Strong at (585) 275-2420.

### Power of Two "Rochester Debut" Saturday, May 12, 2012

"Power of Two" is an inspirational story of identical twins, Ana and Isa Stenzel, born with Cystic Fibrosis, and both receiving double lung transplants. Through this amazing documentary, the twins share their story of love and hope to achieve survival. Isa and Ana know the importance of Organ Donation, and the ability to live, breathe and achieve success as authors, sports competitors and bagpipe player, rivaling all other inspirational stories.

FREE ADMISSION—OPEN TO ALL

Our Lady of Mercy High School Auditorium  
1437 Blossom Road, Rochester, NY 14610

6:30pm doors open

(Entertainment from Scott Topel – Acoustic Guitar & Song)

7:00pm Film Begins

8:30pm SKYPE with Isa and Ana Stenzel – LIVE from California

The Cystic Fibrosis Family Connection is sponsoring the viewing of this film in the Rochester, area and shares the continued success in the fields of Cystic Fibrosis and Organ Donation – "The Gift of Life".

Thank you to all the sponsors who are making this possible: Finger Lakes Donor Recovery Network, Rochester/Finger Lakes Eye & Tissue Bank, Transplant Awareness Organization, Anonymous Donor, and support from University of Rochester Transplant Department.



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www.retb.org

## March is: National Eye Donor Month

National Eye Donor Month was first proclaimed in 1983 by then President Ronald Reagan. Since then a member of Congress has read a proclamation into the Congressional Record each March to note this special occasion.

Corneal transplant is one of the most frequently performed human transplant procedures. The first corneal transplant was performed in 1905. Since 1961, more than 549,889 corneal transplants have been performed, restoring sight to men, women, and children ranging in age from nine days to 103 years. Over 90% of all corneal transplant operations successfully restore the corneal recipient's vision.

The transplantation process depends upon the priceless gift of corneal donation from one human to the next. Cataracts or poor eyesight doesn't prevent you from being a donor.

GIVE THE GIFT OF SIGHT

## April is: National Donate Life Month

National Donate Life Month (NDLM) was instituted by Donate Life America and its partnering organizations in 2003 with the support of then Secretary of HHS, Tommy Thompson.

Celebrated in April each year, NDLM features an entire month of local, regional and national activities to help encourage Americans to register as organ, eye and tissue donors and to celebrate those that have saved lives through the gift of donation.

What can you do to recognize these special months that focus on Giving the Gift of Life?

- 1- Carry a supply of NY State Donate Life enrollment card with you in case someone you meet and speak with wants to enroll – you'll be ready.
- 2- Write a letter to the editor why this month is important to you, your family, your friends, your co-workers.



## 12 Facts About Donation

1. One organ donor can save up to 8 lives. The same donor can also save or improve the lives of up to 50 people by donating tissues and corneas.
2. More than 112,000 people in the United States are waiting for organ transplants. (*Hearts, kidneys, pancreases, lungs, livers and intestines*).
3. 18 people die every day while waiting for organ transplants in the U.S., and every 13 minutes, another name is added to the waiting list. In New York State, someone dies every 13 hours waiting for an organ transplant.
4. Each year, more than one million people need lifesaving and life-improving tissues, and corneas. (*Tissues: Heart valves, blood vessels, bone, corneas, tendons, ligaments and skin*).
5. **Only 18% of New Yorkers age 18 and over have enrolled in the New York State Donate Life Registry, while nationwide the average is 42%.**
6. Donation is only considered after all efforts to save the patient have failed and the patient has died. Saving a patient's life is the health care provider's first priority.
7. The factors that determine who receives an organ include severity of illness, time spent on the waiting list and blood type. Financial or celebrity status has no bearing on determining who receives a transplant.
8. Donation takes place under the same sterile conditions as any medical procedure. Donation generally does not affect the funeral arrangements or viewing. However, the funeral director may need additional time to prepare the body.
9. There are no costs to your estate or family for you to be a donor.
10. All major religions support donation.
11. It is illegal to buy and sell organs in the U.S. The system for matching donor organs and potential recipients is regulated by the Federal Government.
12. The success rate for organ transplants is between 80 and 90 percent.

**KEEP LIFE GOING! Learn how to become an organ, tissue and cornea donor today!**

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NETWORK  
  
www.DonorRecovery.org



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or Current Resident



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES: \$20 Family \$100 Institution 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)