



# Transplant Times

August/September 2017

A newsletter of the Transplant Awareness Organization of Greater Rochester

[www.tao-rochester.org](http://www.tao-rochester.org) | 1.888.664.1463

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## Membership Meetings

Guest Speakers / Topic

### August

- no meeting

### September 18

- Perfect Match: Innovative Liver Regeneration and the Future of Liver Transplantation  
Roberto Hernandez-Alejandro MD

## 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

Fall is rapidly approaching and we are excited for a new "season" of TAO.

We don't hold a member meeting in August, but will resume the meetings in September. The board will meet in August and do some planning for the future. We welcome any suggestions for speakers or topics that you would like to have at a future meeting.

I'm amazed at how quickly this year has flown by, especially the summer! Golfing, family visits, car shows and some work, monopolize my time. We all have things to keep us busy.

We had a good response from our members in our election. I'd like to welcome Marilyn Moran to the board. Marilyn is a tissue and bone recipient and friend. She will be a great asset to our board. Thank you for taking the time to send in your ballots, your vote does count!

I had an opportunity to talk to the Pulmonary Fibrosis Support Group at Strong and to learn a little of their



struggles. Gretchen, Erin and I have also spoken to the Heart Transplant/VAD Support Group at Strong regarding TAO. We look forward to seeing some of their members at a future TAO meeting.

So as Summer draws to a close, take time to soak up the final rays, picnics and fun. Stay healthy and we look forward to seeing you in September!

*Debbie Gendrzewski*



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[www.facebook.com/TAOofRochester](http://www.facebook.com/TAOofRochester)

## TAO Board Election Results

**Thank you for all that sent in your ballots. Here are the results:**

**Marilyn Moran  
Bonnie Haefner  
Debbie Yendrzeski  
Karen Gledhill  
Gretchen Collins  
Judy Munn**




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## Introducing our members

**Vicki DeRue** is a Pittsford/Mendon resident who received a kidney from her son in March 2017. Both Vicki and her son are doing very well. In addition to her son, who lives in Florida, Vicki has a husband, daughter and two grandchildren who reside locally.

Vicki is a former English teacher and school administrator and is currently retired. She looks forward to spending quality time with family and friends.

In addition to the fun times spent with her grandchildren, Vicki enjoys reading, gardening, needlework, and organizing/displaying old photos in albums, slideshows and calendars.

Although she is interested in attending TAO meetings, her availability is limited due to the fact that she spends a fair amount of her leisure time at her second home in Florida.

Welcome, to TAO, Vicki!

## TAO Picnic

The 2017 TAO picnic was held on Monday, June 19 at Buckland Park. As usual, TAO members and their families enjoyed good food and great fellowship. The rain held off and the humidity dropped in time to make for a pleasant evening.

Our compliments to JR's Cooking/Catering for providing a delicious meal!



## Researchers Think They've Found the Cause of Organ Rejection

Receiving a kidney transplant is the preferred treatment for end-stage renal disease (ESRD). However, wait times to receive a transplant can be long and the cost of medication to maintain the transplant is very high. Transplanted organs typically last around 10 years, if taken care of well. However, researchers at the Thomas E. Starzl Transplantation Institute at the University of Pittsburgh may have found the answer to prevent organ rejection.

Fadi Lakkis, the scientific director at the transplantation institute, believed ideally, an organ transplant would last the rest of the patient's life. Not only this, but the drugs that suppress the immune system, which are necessary to keep the transplant healthy, increase the risk of infection and can increase the risk of cancer. In order to reduce the reliance on immunosuppressive drugs and extend the life of these organs, researchers began exploring the cause of organ rejection.

The immune system is made up of two parts: the innate immune system and the adaptive immune system. The innate immune system is the immunity we are born with and is a "first line of defense." Think of skin and some of your white blood cells as the first barriers and defenders to unknown pathogens. The adaptive immune system, however, does the "heavy lifting" by deploying defenses specific to the foreign pathogen. These two immune systems are closely related, and while the adaptive system is what research has focused on for organ rejection, the Pitt research team explored the relationship between both systems and how it affected organ rejection.

The innate immune system is what activates the adaptive system to tell it to reject a transplanted organ. Researchers took mice who received heart, kidney and bone-marrow transplants and identified the protein, called SIRP-alpha, which sets off the chain reaction leading to organ rejection. Lakkis hypothesized that the binding of SIRP-alpha to white blood cells occurs when the protein present in the recipient's body is different than that in the transplanted organ. He believes the next step would involve determining how many different variations of the SIRP-alpha protein exist in humans.

Lakkis believes that through this sequencing and research, matching SIRP-alpha proteins could reduce the chance of organ rejection and lead to lower doses of immunosuppressive medications.

*Science Immunology* 23 Jun 2017:  
Vol. 2, Issue 12, eaam6202  
DOI: 10.1126/sciimmunol.aam6202

## New Addition to UR Medicine Heart and Vascular

UR Medicine Heart and Vascular is pleased to announce the addition of Igor Gosev, M.D. Prior to joining UR Medicine, Dr. Gosev worked as a cardiac surgeon at Brigham and Women's Hospital in Boston, and was a Instructor of Surgery at Harvard Medical School. Most recently, he was a cardiac surgeon and Assistant Professor of Surgery at UMass Memorial Medical Center.

Dr. Gosev is dual Board Certified in general and cardiac surgery. He has a clinical focus in ventricular assist devices, heart transplantation and minimally invasive approaches to aortic and mitral valve disease.

In addition to authoring numerous publications, he has been involved in several research studies focusing on heart failure and mechanical assist devices, aortic valve stenosis and post-operative outcomes in patients with pulmonary embolism, among others.

Dr. Gosev frequently presents on topics related to thoracic and cardiovascular surgery at the national and international levels.



Dr. Gosev

## Upcoming National Observances

### National Minority Donor Awareness Week

**August 1 - 7**

National Minority Donor Awareness Week, observed annually, creates awareness of the need for more organ, eye, and tissue donors, especially among minorities.

### Hispanic Heritage Month

**September 15- October 15**

Hispanic Heritage Month is celebrated annually in the United States.

## United Network for Organ Sharing

*Candidates listed as of July 18, 2017*

97,048	Kidney
14,272	Liver
3,938	Heart
1,706	Kidney/Pancreas
1,358	Lung
906	Pancreas
260	Intestine
37	Heart/Lung
<b>116,933</b>	<b>TOTAL</b>

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

*Totals may be less than sums due to patients in multiple categories*

## Transplant Support Group Meetings

### "Open Airways" Lung Gathering Group

- **Wednesday, August 16 @ 12 noon**  
Jeremiah's - Rt. 250, Fairport Nine Mile Point Rd., Penfield
- **Wednesday, September 20 @ 12 noon**  
Hong Wah Restaurant, 1802 Penfield Rd., Penfield

**Note:** Day changed from Thursday to Wednesday

### Heart Transplant/VAD Support Group

- **Thursday, August 10 @ 6:30 pm**  
No Meeting
- **Thursday, September 14 @ 6:30 pm**  
Speaker TBD

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

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

**G** act as a support group for transplant candidates, recipients & their families.

**O** provide education and information on transplantation issues that surround it.

**A** promote organ/tissue donation awareness.

**L** *All potential transplant recipients, candidates, family and friends are welcome. Meetings held monthly & include programs of interest to the transplant community.*

**S**

## CONTRIBUTIONS

**We are grateful to those individuals and organizations that generously contribute to TAO.**

Kate Collins

Joshua Jenneret

### In Memory of:

**Stacia Davies-Vogt** by David & Joyce Davies

**Richard Odenbach** by Janice Odenbach



**Amazon shoppers can help support TAO** by using Smile.Amazon.com to make their purchases.

AmazonSmile is a website operated by Amazon with the same products, prices and shopping features as Amazon.com. The difference is that when you shop on AmazonSmile, the AmazonSmile Foundation will donate 0.5% of the purchase price of eligible products to the charitable organization of your choice.

Go to smile.amazon.com and follow the instructions to designate Transplant Awareness Organization as your choice. **Thank you!**

## Board of Directors & Officers

### President

Debbie Yendrzeski

### Vice President

Gretchen Collins

### Treasurer

Karen Gledhill

### Secretary

Sue Muto

### Membership

Norman Breen

Jeffrey Alexis, MD

Linda Barnard

Erin Collins

Karen Guarino

Bonnie Haefner

Marilyn Moran

Judy Munn

Janice Odenbach

## Wishes of Wellness

**Our healing thoughts and prayers go out to:**

Laurie Packard

Jerry Runion

Bonnie Haefner

Dave Spiro




**Our newest members to TAO**

Joshua Jenneret

Kate Collins

## Prescription Disposal

Do you have unwanted or expired prescription drugs? If so, stop by the Webster Town Hall, 1000 Ridge Rd., Webster, NY.

There is a box in the lower level where you can deposit any expired or unwanted drugs.

You can also drop off unwanted prescription drugs in the locked container at the Irondequoit PD, Monday through Saturday from 8 a.m. until 11 p.m.

Additionally, there are drug drop boxes located at the Brighton, Gates, Greece and Ogden police departments. The Livingston County Sheriff's Office also has a drug drop box located outside the sheriff's office.

Please don't flush your drugs!



## My Beautiful Baby Girl has made me be who I am Today

On November 11<sup>th</sup> 1991 my daughter Danielle Marie Harloff was born with **Biliary atresia**. It is a rare disease of the liver and bile ducts that occurs in infants. When Danielle was three days old she turned jaundice and by seven days old she was gray. That is when our doctor told us that her liver is not working. She then sent us to Dr. Marilyn Brown (pediatrics gastrologist) at Golisano Children's Hospital.

Danielle at 5 weeks old went through a procedure called the **Kasai procedure**. During this surgery, the surgeon removes any problem bile ducts outside the liver. The small intestine is then attached to the liver. This provides a path that can allow bile to drain from the liver. In Danielle's case it never took and by seven weeks old we were told she would need a liver transplant.

At that time, we heard about living related donors. The liver is the only organ in your body that can regenerate itself. Twenty five years ago Strong Hospital was not doing living related surgery so we had to go to Wyler's Children's Hospital in Chicago. On April 19<sup>th</sup> we flew to Chicago and that is where we met Dr. Alsono and her team. I would go through a series of test to find out if I could be her donor. We thought I would be the better match because we both are type B blood, but as it turned out I have two arteries coming out of my liver and they knew she would only reject it. We were sent home for her Dad to go through the series of testing back here in New York. During these two months Danielle was doing as well as we could hope as far as not needing to be admitted for any problems. I later learned after meeting several other families how lucky we were because their children were in and out of the hospital. **There were a total of five babies on the transplant list and Danielle was number five.**

Everything started changing after we got back home. Danielle became dehydrated and I was going to be taught how to do NG feedings because she was not eating and every time she did try to eat she got sick.

On June 24 1991 we also found out that Wyler's wanted her Dad to have another angiogram done through them because Strong didn't go far enough with the testing. They also wanted to see Danielle and told me that they would teach me the NG feeding.

We went back to Wyler's and Danielle was admitted so they could teach me NG feedings. Her Dad and I went to the Ronald McDonald house to get some sleep. When we returned the following morning, Danielle was being rushed to ICU because she had gone into kidney and liver failure. After a day the kidneys started working again.

Her transplant was schedule for July 13<sup>th</sup> but after being admitted we had found out that the surgeon was no longer working at Wyler's which meant we had to wait until Dr. Broch came from Germany to teach the procedure to Dr. Piper.

On July 13<sup>th</sup> Dad went into surgery first. It took 6 hours to remove a portion of his liver and get it ready for Danielle. Danielle was in surgery for 5 hours.

The next day she had to go back into surgery. The portal vein was kinked which is the vein they removed from dad's leg to make the bile duct for her new liver.

It is about ten day out from transplant and Daniele ran fevers and her bile is still in the forties. On July 25<sup>th</sup> she went back into surgery to reconstruct the bile ducts.

The following day she was back into surgery.

Ultrasound showed the Appendix artery was blocked.

On August 5<sup>th</sup>, Danielle has still been running a fever and liver numbers are elevated and another biopsy was performed.

August 7<sup>th</sup>, Dr. Alsono told us Danielle would need another liver transplant. This comes just six week after the first transplant.

September 3<sup>rd</sup> we got to go home for a week. We had not been home for three months!

From mid-September 1992 – June 1993, Danielle's stomach looked like she was pregnant and the doctor really never could tell me why. Every so often we had to get it drained. She had many up and down days. At times Danielle would be in the hospital for a day or week. Blood transfusion when needed and many trips back to Chicago.

She had a shunt put in on November 1<sup>st</sup> and then, on November 3<sup>rd</sup> back into surgery because it collapsed.

November 6<sup>th</sup> we found out she had 4 ulcers. That is why she needed blood transfusions.

November 11<sup>th</sup> Happy First Birthday!

Danielle got a central line in January 1993 due to a bad infection. A few days later that line broke and she had to get a broviac line.

On April 28, she was admitted back into Strong ICU, all numbers are up and she is now in critical condition.

May 1<sup>st</sup> her kidneys stopped working and put on breathing machine.

May 5<sup>th</sup> transported by medical plane to Chicago. Back on donor list, in ICU.

May 24<sup>th</sup>, Danielle was released from the hospital and we went back to New York on the 31<sup>st</sup> knowing that if a liver became available we had to get back to Chicago in 4-6 hours. I had the number for Airline line. This is when I told Dr. Whitting that I wanted to get Danielle home to live everyday like it was her last.

We were home for a week and the fevers started. On June 6<sup>th</sup> Dr. Brown decided to admit her. I left Danielle with our nurses on the infant unit to go down and fill out the papers. When I returned they were rushing Danielle to ICU because her blood pressure dropped to 75/25.

June 9<sup>th</sup>—Wow was the only word I could say this morning. Danielle was six times her normal size. It was on this day that I told her it was okay if she needed to leave us and that her Papa, (I had lost my dad a year before needing a heart transplant) is waiting for her. I knew in my heart I wasn't going to have her much longer. She was put on a ventilator and paralyzing meds to keep her comfortable.

June 17<sup>th</sup> we left Danielle about 11pm to go to the Ronald McDonald house for the night. We had her older brother Christopher with us for the day. We were only there five minutes when we got the call saying a liver is available and if we wanted it, it was ours.

On the way to the airport Danielle had gotten a hole in her lung which in reality, was a blessing because she would had never made the flight.

June 23 another liver came available and this time, I passed on it.

On June 27<sup>th</sup> it took nine and half hours to drive by ambulance to Chicago. I did not know till she arrived, that the last three hours of the trip they ran out of oxygen and were using the hand bag.

June 29<sup>th</sup> her bili is 60 and by June 30<sup>th</sup> bili is 75!!

July 5<sup>th</sup> Dad went back home, just wanting me to call when we get a liver.

July 8<sup>th</sup> 1994 this day forever changed our lives.

You got your liver today. Dr. Piper took you to surgery

*(My Baby Girl Continued to page 7)*

**( My Baby Girl Continued from page 6)**

at 1:30pm. I waited at the Ronald McDonald house for a call from daddy to say what time his flight is coming in. Dr. Piper called me at 4:30 and told me that they hadn't gotten your liver out yet and your heart had already stopped once and he was very concerned. I asked if he knew why? I told him to let you go. Danielle had been through eleven surgeries in two and half years. You are tired. Dr. Piper had me go to ICU and wait. Daddy called and said he hadn't left yet that they were having problems with air traffic due to thunder storms. I told him what was going on and to call back in twenty minutes. Dr. Piper came in at 6:45pm to tell me you did not make it. The hardest thing I ever had to do was tell your daddy that his baby girl did not make it.

Daddy arrived in Chicago at 9:30pm. We just held you. I know in my heart you are home.

Danielle has been gone for 22 years and not a day goes by that I don't feel her with me and I know she is watching over her two brothers. Christopher (older brother) was three and half when she passed away and is now 26 and getting married in July. Christopher has the biggest kindest, gentle heart. He loves working with kids. His biggest passion is coaching Batavia varsity offense line. May 15, 1995 I had her baby brother Ryan who is now 22. And let me tell you he is what we needed to fill the hole in our hearts. Ryan had the twinkle in his eyes that no matter what he did you could not yell at him. He would just give you that smile that would melt your heart and with that you could only laugh.

When I say she has made me who I am today, it is because I believe that she has brought me a whole bunch of kids to be in my life, whether it was to babysit, or simply just become that second mom. It takes a village to raise a child. And I am so thankful to everyone that has helped raise my three beautiful amazing kids with love and support that lasts a lifetime.

I went through a divorce and did get remarried. With that marriage, I became a stepmom and a grandma of two beautiful grandsons.

Danielle's dad is also remarried and has adopted two beautiful girls from Africa.

- Tina Hoke



Danielle was the first child to be featured by the Liver Foundation on a poster and this is the picture that they used for it.

## Transplant Anniversaries

Lisa Faucz	Kidney	August	2008
James Graczyk	Liver	August	2008
Moira Miller	Liver	August	2005
Cosimo Palermo	Liver	August	2014
Shawn Pangburn	Liver	August	2016
David Spiro	Liver	August	1997
Loren R. Taurisano	Liver	August	2016
Thomas Vitti	Heart	August	2014
Lisa Abbey	Heart	September	2008
Tom Arcara	Heart	September	2005
Ernst Baier	Kidney	September	2000
Marianne Benvenuti	Liver	September	2006
Marcia J. Marcheson	Liver	September	2008
Joanne Schum	Lungs (2)	September	1997
Philip Travis	Kidney	September	2012
Debbie Vernam	Kidney	September	2004
James Connolly	Kidney	September	2011

## 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, \$100s.  
Contact Bonnie Haefner at (585) 391-3555

## Transplant Times

### Submission Deadline

**For October/November issue:  
September 8, 2017**

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



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# TAO / Rochester Membership Application

*No one is denied membership because of financial considerations*

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  - \$20 Family / Individual               \$100 Business / Organization
  - unable to make dues payment at this time

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Phone (    ) \_\_\_\_\_ E-mail \_\_\_\_\_

- Candidate     Recipient     Family Member     Donor Family
- Friend     Professional     Business / Organization

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*.