



Transplant Times

October/November 2016

A newsletter of the Transplant Awareness Organization of Greater Rochester

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Membership Meeting

Guest Speakers / Topic

October 17, 2016

- **Dr. Christine Hay**
Infectious Diseases and the Transplant Patient

November 21, 2016

- **Dr. Jeffrey Alexis**
Advances in Heart Transplantation

TAO Meets

3rd Monday of the Month
6:30 P.M.
Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY

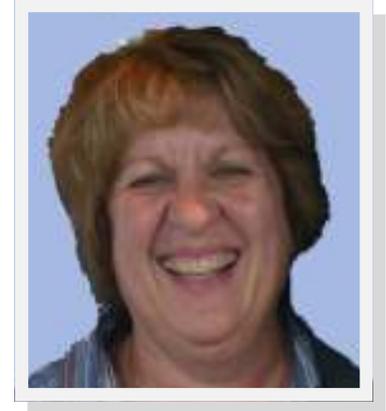
A Message from the President

Goodbye Summer! Hello Fall! After a lovely warm summer, we are headed into fall and winter. With the change of seasons and the holidays rapidly approaching, comes a time of reflection.

Thanksgiving is a time of reviewing our blessings for the year. Thank you to our donors, caregivers, health professionals and our support system. The Gift of Life is immeasurable and just saying thank you doesn't seem like enough, but it is.

As Christmas and Hanukkah approach there are questions. Where has the year gone? Will I get my organ this year? Will I ever feel good or normal again? What will next year bring? No matter what we are facing in our daily lives, I'm sure we have all asked one or more of these questions, but what we have learned is that we have no answers. It's out of our hands. We need to live each moment like it's our last and enjoy it!

Please make time for yourself and take care of yourself. Flu season is upon us so get your flu shot. Check with your team first for their recommendation.



Pneumonia shots are also recommended at some ages, again check with your team.

The TAO Board wishes all of you safe, healthy and happy holidays! We hope to see you at a future meeting or event. Feel free to contact us with any suggestions, topics for speakers, or with any questions that you may have.

Debbie Gendrzewski

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

A Tale of Two Transplants

It's an experience I had hoped to never go through again, but fate it seemed, had other plans. It saved my life, twice in 19 years. It had me telling Mother Nature to cut it out already! Unfortunately, so much of this was out of my hands, and in the hands of my surgeons, my transplant team, and most importantly, the two donor families that who, in the midst of an unspeakable tragedy, saw through their own pain and loss to help another person(s) live on.

This story actually starts in 1985. I won't bore you with all the details, but will try to encapsulate them.

I had only recently graduated from college, and was at home in the Bronx, living with my parents while I pursued becoming a full time paramedic. My family and I were out to dinner on my 26th birthday, when I went to scratch the back of my neck, and felt all the lymph nodes on the right side of my neck. Being the good paramedic that I was, I knew something wasn't right, so I went to my primary MD, and she ran a whole series of tests. The only things that were out of whack were my LFT's, my liver function tests. We watched them as they see-sawed for about six months, and she then decided to send me to a liver specialist down at Mt. Sinai Hospital in Manhattan.

A series of grueling tests later, I was diagnosed with PSC – Primary Sclerosing Cholangitis. My head started spinning, as I had never heard of this disease, much less what I could do to me. Essentially, it is an autoimmune disease of the bile duct system of the liver. It causes scarring, twisting and blockage of the ducts (cholangitis), fevers, and along with some of them most intense abdominal pain you can possibly imagine. The hepatologist then told me that I *might* need a liver transplant somewhere down the line. He was very non-specific about it, so I didn't worry all that much.

Flash forward about ten years later. I'm married, working, and I start getting the symptoms that are classic hallmarks of liver disease, along with that abdominal pain I wrote of. My hair started to fall out, and jaundice started to creep in. Denial being the powerful coping mechanism that it is, wouldn't let me admit that things were beginning to go very, very wrong. Finally, in September of 1996, I got re-evaluated, and was told that I needed a transplant within a year, or its good-bye Dave. As stunned as I was, I pushed on. I was married at the time, and this was as unsettling for my wife as it was for me. She was experiencing my illness through the eyes of a caregiver. That can be an experience that could be just as horrible in its own way.

I was formally listed for transplant in February of 1997, and then was admitted into Mt. Sinai on about the 20th of July, as things got worse. Then, in the late night of July 31st, my surgeon comes into my room, and tells me that they found a liver for me. Astonishment, joy, and fear all wrapped up in one neat package. Then there was the

wait. The donor was still being evaluated, and things could still all go south. Fortunately however, things went as planned, and at 7am on August 1st, I was wheeled into the operating room, and about 7-8 hours later, the start of my new life had begun. Three weeks, one rejection episode, and some post-op issues later, I was brought home by my own paramedics – I was the department head at that point – and settled in to post-transplant life.

We flash forward again to about 3-4 years ago. PSC is one of those diseases that either won't come back, or it will. Fifteen years on from that transplant, and slowly at first, the signs started appearing again. I guess some weight loss, and mild itching (that I ignored), my PSC was creeping back in. My LFT's were starting to become abnormal, and denial, that ole' survival mechanism was functioning like clockwork again, but not without good reason. Things were behaving differently this time around. Even my liver specialist was not 100 percent certain that it was PSC. It took months of repeated and different tests to finally come to that inescapable conclusion that it had indeed returned, and this time, with a vengeance. Symptoms that I had the first time around that were slow to appear came back faster, and what seemed to be more brutally. I also had symptoms that I didn't have to deal with the first time, such as full blown hepatic encephalopathy. This is a vicious effect of the build-up of ammonia in the brain from the lack of the ability to break down proteins properly. I began seeing things that weren't there, hearing things that weren't there, and losing my balance on a regular basis.

Another huge problem if you live here in New York State: We have the lowest rate of organ donation in the country. Go figure, huh? Combine that with issues regarding the distribution of livers in this state, and you have a potential recipe for disaster. As I continued to deteriorate over the course of two years, it was becoming evident that I might actually become a victim of these two factors. I was decidedly sicker than the first time around. My girlfriend Patti, who is my caregiver (sadly, my wife and I had divorced about five years earlier), was facing the real possibility of my death, and just trying to deal with the day-to-day problems of caring for someone who had effectively become something of an invalid. I reached a point where I was unable to drive anymore, and then barely able to stand from the extreme muscle wasting that also accompanies advanced liver disease.

I was admitted into Strong on November 16, 2015 for an infection in my bile ducts. I was so sick at that point, and was feeling my life slip away from me. I can't explain it any other way than that. I became concerned enough to ask for the palliative care team, to find out what my options were. I wasn't giving up hope, but at the same time, I was fully accepting the fact that I could die. Once again however, fate rolled the dice in my favor.

It was Thanksgiving Day. I was eating my not-so-wonderful dinner of something that resembled turkey,

(Continued on Page 3)

University of Rochester Medicine Performs 200th Heart Transplant

By Messenger Post staff

Cardiac surgeons at the University of Rochester Medical Center Strong Memorial Hospital recently performed its 200th heart transplant surgery.

Transplant surgeons Juan Lehoux, surgical director of the Program in Heart Failure and Transplantation; and Sunil Prasad performed the six-hour procedure. Patient Stephen Waite Jr., of Oswego, is recovering at Strong Memorial Hospital.

Waite was 40 when he was diagnosed with non-ischemic cardiomyopathy.

"He went from having a normal life to suddenly struggling with heart failure," said Waite's cardiologist Michael Fischi, of St. Joseph's Physicians Cardiovascular Specialists in Syracuse.



Christine & Stephen Waite Jr.

UR Medicine cardiologists collaborated with Fischi to manage Waite's care for several years. When Waite didn't recover as expected after mitral valve repair, Fischi referred him to Strong Memorial Hospital.

UR Medicine's Cardiac Critical Care Transport Team – a specialized team operating in a dedicated ambulance – brought Waite to Rochester and cardiac surgeons implanted a left ventricular assist device to stabilize his heart function. Transplant cardiologist Eugene Storozynsky monitored Waite's health and managed difficulties with the LVAD for several years.

"It was late at night when doctors told me they had a good heart for me," said Waite. "That night, I was excited knowing that I will get a second chance."

The number of people needing organ transplants exceeds the number of organs donated each year. About 10,000 people in New York need an organ transplant, according to the Finger Lakes Donor Recovery Network – the organ procurement organization affiliated with the University of Rochester Medical Center, in partnership with other upstate New York hospitals.

"I look at Stephen and know that he is well today because a stranger was kind enough to donate a heart," said Waite's wife, Christine. "What was the best day for us was a terrible day for that person's family, and we will think of them always."

About 450 people are on Strong Memorial Hospital heart, liver, kidney or pancreas transplant program waiting lists.

New York state has a shortage of organ donors in its registry. About 27 percent of eligible people have registered to be an organ donor, which is less than half of the national average of 52 percent. In the Finger Lakes region, 34 percent of eligible adults are in the registry.

Low participation in organ donation means patients have

to wait longer for life-saving surgeries. Each day, 18 people in the U.S. die waiting for transplant surgery. In August, the state legislature approved lowering the age to join the registry from 18 to 16 beginning February 2017.

Strong Memorial is the only comprehensive heart failure and transplant center in upstate New York, serving the majority of the state from Northern New York to the Pennsylvania state line.

"We work closely with patients and their families every day, and when a moment like this occurs, it reminds us how many lives we've helped change," said Leway Chen, director of the Program in Heart Failure and Transplantation. "When our transplant recipients share news of family weddings and share photos of grandchildren or trips to wonderful places, it brings a sense of pride and joy to have helped make it possible."

A Tale of Two Transplants

(Continued from Page 2)

and had a cup of pineapple juice in my hand that my girlfriend had brought me, as the kitchen at Strong didn't carry it. In walks the transplant nurse practitioner, whips the juice out of my hand, and tells Patti, who was on the phone with my mother in the Bronx, to get off the phone. A liver had been found. On Thanksgiving Day, no less. Just as before, we waited to get the okay that the liver was good. Just after midnight on the 27th of November, in again I went for surgery. This time however, it was a much longer operation, 14 hours in length, in which I took 40 units of blood, and dumped out about 104 liters of fluid from my body.



Dave Spiro

I needed to have two more operations within the next two weeks or so to close up some tissue, and then spent a total of two months in the hospital. The last 2 ½ weeks were spent in physical therapy, where I learned to walk again, and then another two months of home physical therapy to get me fully back on my feet.

So here I am, ten months later. I am driving again, living my life, about to secure a guitar teacher to finally learn to play that acoustic guitar I've had for so long. My medications have slowly been reduced, and while I still have some side effects that are dogging me, they are slowly fading away. I was told it could be up to two years before I'm finally fully healed. That's a long while, but considering the alternative, I'll just go with it.

I'm still on this side of the earth, as a friend told me, and that's never a bad thing.

Dave Spiro

community events Save the Date . . .

Tuesday, November 29
ROC the Day 2016
Get ready for #GivingTuesday, ROCstars!

Saturday January 14, 2017
Holiday Recognition Dinner



United Network for Organ Sharing

Candidates listed as of 9/23/2016

99,344	Kidney
14,633	Liver
4,091	Heart
1,861	Kidney/Pancreas
1,409	Lung
952	Pancreas
274	Intestine
39	Heart/Lung

119,802 TOTAL

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

www.unos.org

TAO September Meeting



Debbie Yendrzeski, TAO President presenting a Certificate of Appreciation to Dr. Mark Nickels at the September TAO Meeting.
Dr. Nickels' presentation was on "How medications affect our memory."

Board of Directors & Officers

President	Debbie Yendrzeski	Jeffrey Alexis, MD
	Linda Barnard	Linda Barnard
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		Judy Munn
Membership	Norman Breen	Sue Muto
		Janice Odenbach
		Karen Porterfield, LMSW

Transplant Anniversaries

Bernard Blocchi	Liver	October	1996
Claudia Ciresi	Liver	October	1994
Ronald Goehle	Liver	October	2001
Karen Gledhill	Kidney	October	2008
Michelle Halloran	Kidney	October	1997
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
Mary Stein	Liver	October	2005
Kenneth Andrus	Liver	November	2008
Donna Crosby	Liver	November	2003
Peter Davis	Liver	November	1996
Daniel Phillips	Liver	November	2009
Jerry Runion	Kidney	November	1994
Michael Stelljes	Liver	November	2001
Mike Swete	Liver	November	1995
Mark Tagliaferri	Liver	November	2001
Dennis Wittman	Kidney	November	2010
Eric Wright	Lung (2)	November	2006

Our Sympathies

To Mary Harrington's Family

To Peggy DeMare and Family on the death of her husband James

Wishes of Wellness

Our healing thoughts and prayers go out to:

Peter Davis
Tom Barbera



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

TAO www.tao-rochester.org

**G
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S**

To act as a support group for transplant candidates, transplant recipients and their families.

To provide education and information on transplantation issues that surround it.

To promote organ and tissue donation awareness.

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

Gift Ideas

A contribution to TAO in honor of or in memory of a loved one, special person or relative is always a thoughtful gift. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday.

Please make your check payable to: TAO

Mail to: TAO
PO Box 23552
Rochester, NY, 14692-3552

New Solid Organ Transplant Chief Joins UR Medicine’s Department of Surgery

The University of Rochester Medical Center has appointed Roberto Hernandez-Alejandro as chief of UR Medicine’s Division of Solid Organ Transplantation in the Department of Surgery.

Hernandez-Alejandro is an expert in transplantation, with a special interest in caring for patients who have been diagnosed with advanced liver cancer. He is one of the world’s foremost authorities on an innovative procedure called ALPPS, a two-step surgical technique that separates cancerous liver tissue from healthy tissue and promotes the rapid growth of the latter. The surgery is extending lives and improving quality of life, expanding the number of patients undergoing major liver resections that were not previously considered because of risk. He was the first in North America to perform the procedure and is still one of only a handful of surgeons in the world who possesses the expertise.

“We are extremely pleased to welcome Dr. Hernandez-Alejandro and his family to our community,” said Department of Surgery Chair David C. Linehan, M.D., the Seymour I. Schwartz Professor in Surgery at the University of Rochester School of Medicine and Dentistry. “His unique expertise in transplantation and hepatobiliary surgery will bring added value to an already strong program. He is a gifted and innovative surgeon known nationally and internationally for his excellent results, his academic productivity and his leadership skills.”

Most recently an associate professor at Western University in Ontario, Canada, outside of Toronto, Hernandez-Alejandro served as director of Liver Transplantation and Hepatobiliary Surgery at London Health Sciences Centre – University Hospital.

Hernandez-Alejandro grew up in Mexico City, in a family he says stressed hard work and dedication and supported his interest in medicine at a young age. He was self-driven to understand the human body and, ultimately, to work as a surgeon to help patients survive injury and disease, first in general surgery and then following a strong calling as a transplant surgeon.

Hernandez-Alejandro graduated with honors from Universidad La Salle in Mexico City, followed by general surgery training at the Instituto Mexicano del Seguro Social, Centro Medico Siglo XXI. He completed a fellowship in transplantation for kidney and pancreas at the University of Calgary, with a second fellowship in liver transplantation and hepato-pancreato-biliary (HPB) surgery at Western University in London, Ontario. He received further training in living-donor liver transplantation and HPB at the University of Toronto and Kyoto University in Japan.

“I was drawn to URM and UR Medicine because of the culture and passion for excellent patient care, research and education,” Hernandez-Alejandro said. “I am excited to

build upon such a well-known, nationally respected transplant program, to further strengthen what transplant leadership before me has worked so hard to create – a comprehensive team that is laser-focused on providing the best medical opportunities for patients from throughout Upstate New York.”



Hernandez-Alejandro’s clinical interests include liver *Dr. Hernandez-Alejandro* regeneration, colorectal liver metastases, donation after cardiac death and living-donor liver transplantation. His research endeavors are primarily focused on liver regeneration and ischemia reperfusion injury.

In the last five years he has published more than 30 peer-reviewed articles in journals such as the *International Journal of Surgery*, *Annals of Surgery*, *Surgery*, and *World Journal of Surgery*, as well as book chapters on the subjects of liver transplant techniques and liver resections. Hernandez-Alejandro has served over the past five years as an associate and section editor for *TransplantNow*, the Canadian Society of Transplantation’s online journal, and has been a journal reviewer for the *Annals of Surgery*, *Surgery*, *British Journal of Surgery*, and *HPB*, the journal of the International Hepato-Pancreato-Biliary Association.

He has been honored with numerous research and teaching awards, including twice receiving the Rising Star Award from the International Liver Transplantation Society, and was named a Researcher of the Month by Canadians for Health Research.

Hernandez-Alejandro succeeds transplant surgeon Mark S. Orloff, M.D., who was appointed as vice chair for Clinical Operations and Regional Development, a position that will focus on UR Medicine’s Western New York partners and their surgical programs. Orloff continues as a member of the Solid Organ Transplant surgical team.



Flu Season is approaching. Get Vaccinated!

transplant Support Group

"Open Airways" - Lung Gathering Group

Thursday, October 20 @ 12 noon
Jeremiah's - Rt. 250, Fairport Nine Mile Point Rd., Penfield

Thursday, November 17 @ 12 noon
Hong Wah Restaurant, 1802 Penfield Road, Penfield

Heart Transplant/VAD Support Group*

Thursday October 13 @ 6:30 pm
Transplant Awareness Organization

Thursday, November 10 @ 6:30 pm
Transplant Coordinator—Liz Powley, FNP

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

Tuesday November 29



Welcome New Members

David Rowlands



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

Transplant Times

Submission Deadline

**For December/January issue:
November 7, 2016**

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

Donations to help our organization are always welcome, and are tax-deductible. Make checks payable to:
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Name (please print) _____

Address _____ City _____ State _____ Zip _____

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*.