



Transplant Times

August/September 2016

A newsletter of the Transplant Awareness Organization of Greater Rochester
www.tao-rochester.org | 1.888.664.1463

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Membership Meeting Guest Speakers / Topic

August, 2016
No Meeting!

September, 2016

- **Dr. Mark Nickels**
How medications affect our memory

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

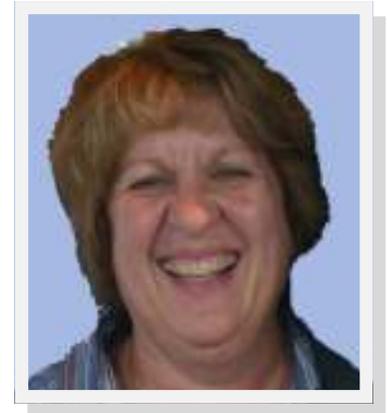
I hope this finds you all enjoying the beautiful summer! The days have been filled with heat, sun and family and I hope the same for you!

TAO is looking forward to Fall and the start of our meetings and social gatherings. We are always looking for suggestions for speakers and presentations that you would like to hear about. We'd also like to hear your transplant story, good or bad, pre or post or the whole journey. You can contact me at auggieday@aol.com. You need not be an author, write your story and the newsletter committee will help you with it. We glean so much from others' experiences!

The Transplant Games are over but another successful year. As I watched from my computer it brought it all back from when I attended the games, the participants were different yet the spirit was the same. I was overcome with emotion as I listened to the stories and saw the camaraderie of the athletes.

The TAO picnic was a nice event, thank you to Bev Shank for chairing this event. Good food and great company!

Harbor House will be holding their



annual fundraiser on September 10, please consider supporting this worthy cause.

As we prepare for Fall in our gardens and homes, please prepare your bodies. Get the flu shot and do whatever you need to stay well over the long winter months ahead. We all have different needs, Vitamin D is what I need over the fall and winter, you may need something else. Check with your physician and take care!

I look forward to seeing you at a future meeting or event and hearing from you with your transplant story!

Debbie Gendrzewski

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

Team Finger Lakes Celebrates at Transplant Games

It was quite a year for Team Finger Lakes at the 2016 Donate Life - Transplant Games of America that took place in Cleveland, Ohio in June. This was the team's third appearance at the Games and the largest group in the team's history. While Team Finger Lakes brought home an impressive 7 medals, it was what took place off the playing field that was the real reason to celebrate. Team Finger Lakes had plenty to celebrate and commemorate when its 37-members recently traveled to Cleveland, Ohio for the Donate Life - Transplant Games of America. The team included 15 transplant recipients, 3 living donors, 11 donor family members and 8 supporters, making it the largest number of regional participants in the past 3 previous games.

The Transplant Games of America features a variety of competitive events for Individuals who have undergone life-saving or life-improving transplant surgeries. Team Finger Lakes competed in a 5K and 10K run/walk, bocce, bowling, corn hole, cycling, darts, golf, swimming, table tennis, tennis and track and field. In addition to sporting events, the Games also include special tributes to donors and ceremonies for donor families to honor them for making the gift of life possible.

For the members of Team Finger Lakes, the Games were much more than a series of competitions and events. It was an opportunity to celebrate and be grateful for second chances and the heroes who passed life on. Amy James, the team's manager and Community Education Manager for FLDRN, says that while none of the team's transplant recipients are directly connected to the team's donor families, they have all come together as one family. "This team is amazing," said Amy. "They support one another, celebrate each other's accomplishments and are incredibly grateful for the second chances that donors and donor families have given others." All of that was evident at the 2016 Games. Here are just a few highlights: **Standing Ovation for Donor Families:** The Opening Ceremonies at Cleveland's Public Hall welcomed teams from across the country. But it was the introduction of donor families that brought the audience to their feet – many of whom in the crowd would not have been there to give the standing ovation if it were not for the generosity of these families and their loved ones who gave the gift of life. Team Finger Lakes donor family members were: Holly, Andy, Ben and Alex Campbell; Donna Dunn; Carol, James and Jamie Johnson; Karen Kline; and Michelle Lester. **Quarter Century Club:** Team Finger Lakes members **Karen Gledhill** (36 years combined, 2

kidney transplants); Jodi Manis (30 year kidney recipient), Joy Piekunka (30 year living donor to sister Jodi Manis) and Kathy Reimer (35 year kidney recipient from her sister) were inducted into the "Quarter Century Club", which recognizes recipients and living donors who are 25+ years post-transplant.

Donor Parents Share in Recipient's Triumph:

Holly & Andy Campbell (donor parents) were among the first to congratulate 8 year-old Beckham Scadlock (of Iowa) after he won a bronze medal in swimming. The Campbell's son, Jake, passed away in 2007 at 11 weeks of age and donated his heart to Beckham, who was only 2 weeks old at the time. Karen Kline (Donor Mom) & Robert Juneau (recipient): When Karen proudly presented Robert his bronze medal for Table Tennis, he, in turn, removed it from his neck and placed it over Karen's head for her to keep. **Mother/Daughter Team:** Kathleen Goodnough (recipient) and Meaghan Greeley (living donor) made the trip to the Transplant Games together to celebrate their 10th anniversary since Meaghan donated part of her liver to Kathleen. When Meaghan finished the 5K ahead of her mom, she circled back to wait so they could run Kathleen's last 100 yards together. **Former Runner Back on the Course: Fred Knewstub** (recipient) had been a marathon runner before he found out he needed a heart transplant. Only two years after receiving his new heart, Fred ran the 10K at the Transplant Games and won the bronze medal in the in his age division.

The next Donate Life - Transplant Games of America will take place in 2018. Are you a recipient, living donor or donor family who would like to join Team Finger Lakes? Please contact Amy James at amy_james@Rochester.edu.

Team Finger Lakes Facts

Team Finger Lakes 2016 Medal Recipients:
 Meaghan Greeley: Gold & Silver (swimming)
 Robert Juneau – Bronze (table tennis)
Fred Knewstub: Bronze (10K)
Tim Parks: Bronze (bowling)
Tina Serio: Silver (bowling)
 Eric Wright – Gold (racquetball)

Oldest Team Member: **Mike Stelljes** - 79-year-old liver recipient.

Youngest Team Member: Meaghan Greeley - 30-year-old who donated a portion of her liver to her mother, Kathleen Goodnough. This year marks their 10-year anniversary since the transplant.

Note: *TAO members are in bold*

Appointment - Sunil M. Prasad M.D.



Sunil M. Prasad, M.D., has been appointed chief of the Division of Cardiac Surgery at UPMC. He will lead the cardiac surgery program at Strong Memorial Hospital and will serve as associate professor of Surgery in the School of Medicine and Dentistry, pending approval of the University's Board of Trustees.

After medical school at the University of Illinois, Sunil trained in cardiothoracic surgery at the Washington University School of Medicine and Barnes-Jewish Hospital. He was later appointed to the medical school's faculty and served as an attending heart surgeon at Barnes-Jewish Hospital, whose program in adult cardiology and heart surgery is ranked 14th in the nation by *U.S. News and World Report*.

While Sunil performs a range of complex surgical procedures, including heart transplants, he has special expertise in the use of mechanical devices to help patients who are in heart or respiratory failure. He led Barnes-Jewish Hospital's program in ECMO and has helped pioneer the next generation of ECMO, known as "walking ECMO," which uses portable devices that allow patients to get out of bed and walk with their device, often reducing complications and improving outcomes. He was recently the senior author of a review on the use of walking ECMO in the journal *JAMA Surgery*.

Immediately prior to joining UR Medicine, Sunil served for two years as director of ECMO/LVAD at Mercy Springfield Hospital, in Springfield, Mo. "Dr. Prasad is an outstanding addition to our team, bringing a wealth of experience in surgical treatment for people with life-threatening heart disease," said David C. Linehan, M.D., chair of the Department of Surgery and Seymour I. Schwartz Professor in Surgery. "UR Medicine is known for its leadership in comprehensive heart care," said Sunil. "I want to complement and build upon the team to make the program even better."

Sunil has published more than 40 academic papers on topics including the prevention of complications from LVADs, the use of radiofrequency ablation to treat atrial fibrillation, and ways to improve the preservation of donor hearts used in transplants. He serves on the Council on Cardiothoracic and Vascular Surgery for the American Heart Association.

Sunil succeeds George L. Hicks, M.D., who has served as chief of Cardiac Surgery since 1991. George has been instrumental in bringing new technologies to advance cardiac surgery and improve patient outcomes. He will focus on education and training through the School of Medicine's Cardiothoracic Surgery Residency Program.

"Dr. Hicks' leadership brought continuous advances in care and research, which are essential to our mission," David said. "His commitment to teaching and mentoring surgeons is unparalleled and a significant benefit to UPMC residents."

Benefits and Challenges After an Organ Transplant



Most people share a common misconception after organ transplant surgery, according to Marwan Abouljoud, MD, director of the Transplant Institute at Henry Ford Hospital System in Detroit.

After their transplant, most people just do not understand the magnitude of the surgery they went through. Many think recovery is a matter of a few weeks.

Emotions After an Organ Transplant

The good news: "The majority of people feel better after an organ transplant," says Gigi Spicer, RN, director of the Virginia Transplant Center at Henrico Doctors' Hospital in Richmond, Va.

A typical comment she hears is this: "I didn't know how badly I felt." With that increased sense of well-being, patients are often euphoric.

While that sense of elation is wonderful, Spicer says to remember that you can't push your body faster than it wants to go.

Medications After an Organ Transplant

Like all organ transplant patients, you left the hospital with multiple medications. Perhaps some are to treat underlying conditions such as blood pressure and you are accustomed to taking them.

But the other medications are immunosuppressant drugs to keep your body from fighting off the new organ. A heart transplant patient can leave the hospital with 10 or 15 prescriptions, Diane Kasper, heart transplant coordinator at Mayo Clinic Hospital, tells WebMD.

To avoid problems post-transplant, you must take the medications as prescribed. It can help if you ask your doctor or the pharmacist exactly what each medication is for and to describe possible side effects so you can be aware of them and report them.

Also ask your doctor or pharmacist if you should take the medications with food and if it's still OK to take your routine vitamins, calcium, and other supplements.

Your Post-Transplant Routine

Expect to have an ongoing relationship with your organ transplant team. Depending on the type of transplant and your health status, you will be given a schedule of follow-up exams.

For example, if you had a heart transplant, you might meet with your health care providers twice a week for two months. Blood work is needed to follow your progress. Perhaps you'll go to a support group. And always, you have to be on guard against infection.

For the rest of their lives, organ transplant patients have to watch out for infection, Kasper says. That means no sushi and no salad bars. It means avoiding contact with sick people. You also can't be around people recently vaccinated with live vaccines, because that person is shedding the live virus.

It's crucial to promptly report side effects with post-transplant medications, says Spicer. And it's important to keep underlying medical conditions, such as diabetes and high blood pressure, under control. If

(Continued on page 7)

community events
Save the Date . . .

Saturday September 10, 2016
And The BEAT Goes On. . .



6 p.m.at the Doubletree Hotel
1111 Jefferson Road, Rochester, NY 14623

A Fun Evening to help support the work of the
Harbor House of Rochester
Purchase your tickets online at brownpapertickets.com,
or contact Harbor House at (585) 473-1779.
Ticket pricing: \$35.00 prior to September 1, 2016 and
\$40.00 thereafter.

Tickets will not be available at the door!

United Network for Organ Sharing

Candidates listed as of 7/22/2016

| | |
|---------------|------------------------|
| 99,478 | Kidney |
| 14,637 | Liver |
| 4,120 | Heart |
| 1,880 | Kidney/Pancreas |
| 1,409 | Lung |
| 972 | Pancreas |
| 272 | Intestine |
| 42 | Heart/Lung |

120,001 TOTAL

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

www.unos.org



About Harbor House of Rochester
A Rochester Community Project of Caring

For many patients receiving medical care such as heart failure, organ transplant, or mechanical assist devices at the University of Rochester Medical Center, an emergency situation can arise and may last for months. This situation is often an emotional and financial hardship for the patients and their families.

Harbor House of Rochester Inc., founded in 2008, is a not-for-profit organization dedicated to helping patients and families who are experiencing this hardship.

The mission of Harbor House of Rochester, Inc. is to provide temporary lodging for families of adult critical care patients who live outside the Rochester area and are receiving care at the University of Rochester Medical Center and other area hospitals.

Harbor House provides a "home-away-from-home" environment of safe and supportive living that eases the emotional and financial burdens on these families.

Member of the National Association of Hospital Hospitality Houses Incorporated (NAHHH) since May 2008.



Harbor House of Rochester
89 Rossiter Road
Rochester, NY 14620-4125
Phone: (585) 473-1779

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Transplant Anniversaries

| | | | |
|---------------------|-----------|-----------|------|
| Lisa Faucz | Kidney | August | 2008 |
| James Graczyk | Liver | August | 2008 |
| Moira Miller | Liver | August | 2005 |
| Cosimo Palermo | Liver | August | 2014 |
| David Spiro | Liver | August | 1997 |
| 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 |
| James Connolly | Liver | September | 2011 |
| Marcia J. Marcheson | Liver | September | 2008 |
| Joanne Schum | Lungs (2) | September | 1997 |
| Philip Travis | Kidney | September | 2012 |
| Debbie Vernam | Kidney | September | 2004 |

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**G
O
A
L
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.*

Our Sympathies

To Judy and family on the death of
Phil Sinaguglia

To the Richard Perez family on the death of
Richard's wife Maria Aponte

Wishes of Wellness

Our healing thoughts and
prayers go out to:

Phyllis Breen
Geoff Foley
Karen Gledhill
Bonnie Haefner
Laurie Packard



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

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

TAO PICNIC, NICE KICKOFF TO SUMMER

About 30 TAO members, their families and friends enjoyed this annual gathering held on Monday, June 20, at the Buckland Lodge in Brighton, NY. The weather was seasonal, the food tasty and desserts – as always – plentiful. Tableside conversations while munching appetizers were abundant. Those of you who couldn't attend this year, we hope to see you next year!



Amanda Packard update

I thought it would be fun to update the members of TAO on what has been happening to one of the babies born in 1994. Amanda graduated on May 20th from R.I.T with a BS in Museum Studies. She graduated Magnum Cum Laud. She is currently working at Vanity and David's Bridal while applying for jobs at museums in California, Chicago, and Washington D.C. I am also happy to announce that she recently became engaged to her boyfriend (Henry) of 6 years. No date has been set.

Laurie Packard update

I received an AAS in Medical Coding and Reimbursement from Bryant & Stratton online program in April. I am not working yet but will be looking for a remote job after I take my certification exam. My transplanted kidney is failing and I went back on dialysis in November 2015, I go to the Eastview Dialysis Clinic. Ed note: Laurie served as TAO Membership Chair for many years and Amanda has supported TAO with projects during her school years.



Top: Amanda Packard and her Dad, Doug
Bottom: Laurie Packard

Benefits and Challenges After an Organ Transplant

(Continued from page 3)

you lost a kidney because of diabetes, for example, and you don't keep your sugar under control, you are going to hurt your kidney again. The surgery has not left you invulnerable.

Organ transplant surgery is a trade-off, Kasper says. But if you realize the surgery is done to give you a better quality of life, it can make it easier to follow all the new health measures you are now expected to heed, such as taking your immunosuppressant medications on schedule.

Be sure to cultivate a strong support system, especially for right after the surgery, says Penelope Loughhead, LMSW, an organ transplant social worker at Memorial Hermann Hospital in Houston. She suggests having someone learn about your medications with you, so they can be a safety net for you when you get home.

transplant Support Group Meetings

"Open Airways" - Lung Gathering Group

Thursday, August 18 @ noon

Jeremiah's - Rt. 250, Fairport Nine Mile Point Rd., Penfield

Thursday, September 21 @ 12 noon

Corner Bakery Café - 3300 Monroe Ave. Pittsford

Heart Transplant/VAD Support Group*

Thursday, August 11 @ 6:30 pm

TBD

Thursday, September 8 @ 6:30 pm

LVAD Specific Support Group
ACF A & B Conference Room (Above Main Lobby)
(Invite to follow with more information)

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

Contributions

Cosimo & Nancy Palermo

Peter Davis

Welcome New Members

Cindy, Philip, and Nicholas LaTona live in Churchville. Nick was diagnosed with kidney disease when he was 11 years old and is now in his early 20's. He received a kidney from his Mom in April of this year.

Cindy and Nicholas are doing well in their recovery, and Cindy hopes to be able to return to work in the accounting department of a machine shop. Nick has bachelor degrees in fine arts and public relations.

Although Nick plans to return to work in August, he is considering returning to college to pursue a career in the medical field. Philip is retired, but uses his free time to perform in a rock band, a positive for Cindy who loves to dance.

Frances Sheppard is a new member who is awaiting a kidney transplant. Originally from South Carolina, Fran moved to Rochester and attended college here. She is a retired nurse and her husband, Luvon is a Professor in the College of Arts at R.I.T. Needless to say, they have a wonderful collection of art in their home.

While waiting for her transplant, Fran keeps herself busy by volunteering at the Montgomery Senior Center gathering needed supplies and taking meals to shut-ins. She also runs a boutique shop that carries authentic articles from Africa. Please welcome Fran and Luvon to our organization.

Transplant Times

Submission Deadline

**For October-November 2016 issue:
September 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

- DUES:**
- 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*.