



Transplant Times

A newsletter of the Transplant Awareness Organization of Greater Rochester

June/July 2018

www.tao-rochester.org | 1.888.664.1463

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Membership Meetings

Guest Speakers / Topic

June 18
- Picnic

July
- No Member Meeting

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

Finally we are warming up!! Flowers are blooming and the grass is growing. Are you up for a picnic? TAO will be holding the annual "end of the year" picnic Monday, June 18, details are inside. Hope to see you there!

We don't hold member meetings in July and August but the board is busy planning for the Fall. If you have any suggestions for speakers or events, please let someone on the Board know, we are always looking for new ideas. This is your organization!

Enclosed you will find a ballot, please fill out and return. We can't function without a Board and your vote counts!

Life changes in an instant, one never knows what will occur. We all deal with challenges either with ourselves or loved ones.

Take the time this summer, take care of yourself so you can take care of others. Relax and enjoy the warm weather and sunshine.



This season is short and it deserves to be enjoyed as is life!

Please remember to wear your sunscreen to protect against skin cancer.

The TAO Board looks forward to seeing you all in the Fall. Have a safe, and fun Summer!

Debbie Gendrzeski



Visit, like our Facebook Page
www.facebook.com/TAOfRochester

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



Jim McGrath presented *The future of dialysis treatments* to TAO during the April meeting. Please check the TAO website for his slides.



Sharon Wesline, CCH is pictured with TAO President Debbie Yendrzkeski at the May TAO meeting.

Sharon spoke about *Caring for the Caregiver* and how important it is to take care of ourselves.

If you could use a break or need time for yourself please contact Sharon at Intuitive Soul Connections.

Recipes

For those present at the February Member Meeting and enjoyed the potatoes that were served — below find the recipe. Enjoy!



Hash Brown Casserole

Ingredients:

- 2 lbs. frozen hash browns
- 1/2 cup butter, melted
- 1(10 1/4 ounce) can cream of chicken soup
- 1 pint sour cream
- 1/2 cup chopped onion
- 2 cups grated cheddar cheese
- 1 teaspoon salt
- 1/4 teaspoon pepper

Directions:

Preheat oven to 350 degrees and spray an 11x14 baking dish with cooking spray. Mix the above ingredients together. Place in prepared pan and bake for 45 minutes or until brown on top.

NUTRITION INFO

Serving Size: 1 (173 g)
Servings Per Recipe: 10

AMT. PER SERVING	% DAILY VALUE
Calories 488.4	
Calories from Fat 339	70%
Total Fat 37.7g	58%
Saturated Fat 16.5g	82%
Cholesterol 49.9mg	16%
Sodium 751.2mg	31%
Total Carbohydrate 30.0g	10%
Dietary Fiber 1.9g	7%
Sugars 3.6 g	14%
Protein 10.3g	20%

Our Sympathies

TAO wishes to extend their condolences to the families of:

Leon Sturgill
Janice Reif
Matt Felo Sr.



TAO ANNUAL END OF YEAR P I C I N I C

Monday, June 18
at **Buckland Park**
1341 Westfall Road
Rochester, NY 14618

Come at 5:00 pm
Dinner at 6:00pm
Bring any games that you'd like to enjoy.
All are invited!!

RSVP by June 10 with check
\$15 per adult /\$8 child to:
TAO
PO Box 23552
Rochester, NY, 14692-3552

We hope to see you there!

Lilac Festival Parade

The Lions Eye Bank of Rochester along with the Transplant Awareness Organization (TAO) sponsored a float in this year's Lilac Festival Parade on Saturday, May 12.

Riders included organ, cornea, and tissue recipients, their family members and donor families. full of recipients and their families.

The float was beautifully decorated by the riders. Along the parade route, riders thanked the community for its support of donation and the Gifts of Life and Sight. From the crowd came much applause—a true testament to our community embracing donation. We hope you'll join us next year!



Transplant Times

Submission Deadline

For August/September issue:
July 8, 2018

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

We welcome your personal story and feel our members appreciate hearing about other's journey. So write your story and send it to us, a picture is always welcomed too!



Upcoming Events

Monday June 18 - Picnic

**Buckland Park, 1341 Westfall Rd.
5:00 pm, Eat at 6:00pm
See details on page 3.**

Sunday August 5– River Run

**Saturday, September 29
And the Beat Goes on ...
at the Monroe Golf Club
Fundraiser to benefit Harbor House
Check for details on their website:
www.harborhouseofrochester.org**

United Network for Organ Sharing

Candidates listed as of May 10, 2018

95,157	Kidney
13,956	Liver
3,984	Heart
1,659	Kidney/Pancreas
1,433	Lung
886	Pancreas
248	Intestine
55	Heart/Lung

114,735 TOTAL

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, June 20 @ noon**
Hong Wah, 1802 Penfield Rd, Penfield
- **Wednesday, July 18 @ noon**
Jeremiah's, 2164 Fairport Nine Mile Pt. Rd.

Heart Transplant/VAD Support Group

- **Thursday, June 14 @ 6:30 pm**
Mark Nickels, Transplant Psychiatrist
- **Thursday, July 12 @ 6:30 pm**
Advanced Heart Failure Program Director
Leway Chen, MD, MPH

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

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

S

Introducing our new board candidates

Chuck Lundeen retired after teaching English and French for 30 years. The major portion of his career was spent at the Canandaigua Middle School where he was also President of the Canandaigua Teachers' Association for many years. Following his retirement Chuck spent several years as an adjunct faculty member in the English Department at Nazareth College where he supervised student teachers and co-taught the English Methods Course. He also served as a substitute in several Rochester suburban school districts.

In 2002, Chuck was put onto the waiting list for a liver transplant after having lived with Primary Sclerosing Cholangitis for many years. In 2008, he received his new organ thanks to Dr. A. Bozorgzadeh and a wonderful team at Strong Memorial Hospital here in Rochester.

Along with his husband, John Williams, a retired attorney and fundraiser, Chuck enjoys the many performing arts opportunities in Rochester. For several years Chuck taught a course in Opera at OASIS, where he was honored as the 2017 Volunteer of the Year. John and Chuck were also honored as 2017 recipients of one of the Rochester Area Community Foundation philanthropy awards. Chuck is also an avid gardener.

Melanie Runion is a Fairport resident and was married to Jerry for over 30 years. Jerry was a kidney recipient and former TAO president. She has worked for Dress Barn for over 16 years. Melanie has 2 children and 4 grand - children.



Wishes of Wellness

Our healing thoughts and prayers go out to:

Geoff Foley
Jerry Muto
Shawn Pangburn
Dave Spiro
Bonnie Haefner
Mike Swete
Debbie Yendrzeski
Linda Barnard



CONTRIBUTIONS

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

Helen Cox
Rich Forbes

In Memory of: Frank Imburgia by
Priscilla Imburgia

Board of Directors & Officers

President	Jeffrey Alexis, MD
	Linda Barnard
Vice President	Karen Guarino
	Bonnie Haefner
Treasurer	Marilyn Moran
	Judy Munn
Secretary	Janice Odenbach
	Melanie Reunion
Membership	
	Norman Breen

Golisano Children's Hospital to Launch Pediatric Liver Transplant Program

For the past decade, children in Upstate New York who needed a pediatric liver transplant didn't have any local options. With no nearby providers, this meant long car trips or plane rides to New York City or centers in other states to get the care they needed — not only for the surgery itself, but also for the majority of the required follow-up visits and treatment.

That will change this summer when UR Medicine's Golisano Children's Hospital launches a new program aimed to help treat children with serious liver problems. Led by Nanda Kerkar, M.D., Professor of Pediatrics, the team hopes to perform its first transplant by July.

"The institution made a commitment to developing a viable liver transplant program for children here at Golisano Children's Hospital, and they really did it in the right way," said Kerkar. "They consolidated the adult liver transplant program by hiring new transplant surgeons and hepatologists, making it into a real strength, and then they built this wonderful new children's hospital building. The next logical step was to start up the pediatric liver transplant program."

Kerkar comes to Rochester after serving as the Medical Director of Pediatric Liver Transplantation at Children's Hospital Los Angeles. Previously, she

held the same position at the Mount Sinai Hospital in New York City from 2006 to 2012. In addition to the transplant program, Kerkar has also led the development of the pediatric hepatology service by starting a pediatric liver clinic.

The clinic, which is equipped with Fibroscan technology to reduce the need for liver biopsies during follow-up, will provide diagnoses and full coverage for children with liver problems. A liver transplant clinic has also been established, which allows those who previously had their transplants elsewhere to stay closer to home for follow-up treatment. The liver transplant evaluation clinic will begin this spring.

"If you have a child with liver problems, obviously you don't just rush to the first transplant center. You want to see an experienced doctor, get the right diagnosis, try the appropriate medical treatments or medications, and if all that doesn't work, then you go to the transplant option," said Kerkar. "So, we're eager to build up the hepatology component of the transplant program as well."

In addition to Kerkar, the Pediatric Liver Transplant team includes transplant surgeon Koji Tomiyama, M.D.; Michelle Eaton, N.P.; Taryn Schieber, R.N.; Jennifer Iuppa, PharmD; Jennifer Aquilina, social worker; and dietician Theresa Harte. The pediatric transplant team is supported by the adult transplant team.



From left: Jennifer Aquilina, Michelle Eaton, Koji Tomiyama, Nanda Kerkar, Theresa Harte, Taryn Schieber, Jennifer Iuppa, Jennifer Cooley, and Mike Grizzanti. Not shown: Kerry Sargent.

To Our Friends & Family

Please don't be angry
 Please don't be mad
 You don't understand this new life we have
 Things are different
 Things have changed
 With this new diagnosis
 Our lives are not the same
 Turning yellow, too much sleep and sunken eyes gray
 When and how could this all happen
 I was healthy yesterday
 Ascites, varices and Hepatic Encephalopathy
 With End Stage Liver Disease
 Only a Transplant Surgeon and his Team can save me
 MELD scores, phones in hand, waiting on "The List"
 Oh please God, please Dear God
 Don't let my name be missed!
 Our phone rings and rings
 While we wait for the call
 We are waiting for a Liver
 That is not too big or small
 When we least expect it
 The important Call comes in
 We rush to the hospital terrified and excited
 And Let the FUN begin!
 Blood draws, needles and IV's, way too many to count
 The life-saving Transplant begins
 While Friends and Family wait it out
 The Transplant is over
 I'm still alive
 Over the next few hours and days
 Will we all survive?
 8am & 8pm are the rejection medication times
 Don't be too early or too late
 To keep living your life and staying alive
 We survive day by day
 Sometimes by hour or by minute
 You wouldn't understand us unless you are also living in it
 Livers, and organs everywhere
 When you are alive, do you dare
 Become an organ donor
 To show how much you care?
 Will you need your organs when you're dead and gone
 All organ donors and their families enable life to go on
 We are ever so thankful, yet ever so sad
 Life was revived when our Angel Donor died
 To our Donor Families and Angel Donors
 We send our heartfelt thanks and prayers
 We are ever so grateful for all the lives you save
 Each day we send you our prayers

Don't be angry
 Don't be mad
 We are so grateful for this Transplant
 And the life our Donor had
 We are oh so different
 We have oh so changed
 Please continue to love us
 Even though we are not the same
 The Donor and Donor Family are our angels
 The Transplant Surgeon and Team are there
 They save many so lives
 They show us how much they care
 Please don't be angry
 Please don't be mad
 We are grateful and such different people
 With this new transplant life we have

*By Dawn Conciatori
 2015*

Transplant Anniversaries

Thomas Clark	Kidney	June 2007
Cynthia Golas	Kidney	June 2017
Kristin House	Kidney	June 2014
Kevin McCorry II	Bone Marrow	June 2004
Dick Miller	Heart	June 2007
Larry Rosner	Kidney	June 2014
Karen Lee Sommer	Liver	June 2006
Ralph M. Toscano Jr.	Cornea	June 1990
Joanne Tucker	Liver	June 2006
Mike Yendzieski	Liver	June 2002
Rick Clark	Kidney	July 2004
James Connolly	Liver	July 1990
John Dedloff	Heart	July 2011
Matthew Felo	Lung	July 2007
Bonnie Gottorff	Kidney	July 2005
Cheryl Helfer	Kidney	July 2002
Dean Kiefer	Kidney	July 2011
Daniel Klimek	Cornea	July 2011
John Odell	Liver	July 2010
Richard Perez	Liver	July 2003
Patricia Ridge	Kidney/Pancreas	July 2006
Philip Ronzo	Liver	July 1996
William Sprenger	Heart	July 2015
Karen Guarino	Bone Tissue	July 2016



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***It's time to renew your membership for 2018!
Help support the TAO mission***



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

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

Donations 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) _____

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*.