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TRANSPLANT SUPPORT ORGANIZATION

Serving Westchester, Putnam, Dutchess,
Bronx Counties and Southern Connecticut



VOL. 25, ISSUE 2

FALL, 2020

Message from the Co-Presidents

It's been 6 months since the start of this extraordinary period of time in history. We know you've all made major adjustments to your lifestyles, and it's been quite stressful at times.

TSO has also made changes in its activities. Our face-to-face gatherings will have to wait for the foreseeable future, but we do hope we'll be able to bring us all together sometime next year.

We've adopted the electronic age fairly quickly with our Zoom meetings, both for our general meetings and for our TSO board meetings. And this has opened up new opportunities for us, to be able to invite members and guests who may have found it inconvenient to come to Greenburgh, New York on a Wednesday evening.

So please stay with us. We're asking you even to consider joining TSO with your membership. Our newsletter has all the information you need about joining us with your dues.

And we'll continue to explore new ways you can participate and volunteer for transplant activities. It may be slow for a time, but we'll get there with the same sense of thankfulness for our gift of life and a second birthday celebration.

COMMUNITY ACTION RESPONSE: COVID-19 **5 things you can do to make a positive difference in your community**



TSO HOLIDAY PARTY

TSO Holiday Party is cancelled.

The TSO board decided to cancel the holiday party usually held in December of each year.



But please watch for a future email and MailChimp to announce a virtual get-together. This will allow us to still be thankful for ourselves, our family and friends, and our gift.

For information, please check our website:

www.transplantsupport.org

To contact us by mail please write to:

TSO, 1335 Mace Avenue, Bronx, NY 10469

Or email us: email4tso@gmail.com

We are also on Facebook. Check us out for information and updates.

You do not need to have a Facebook account to visit TSO on Facebook

To all recipients of this newsletter.

Please send your email address so we may notify you of any last minute changes to our meetings. If you have changed your address recently please let us know so we can update our records.

Please send all correspondence to: email4tso@gmail.com



PAY IT FORWARD

"I COULD NEVER ADEQUATELY PAY HIM BACK, SO I JUST HAVE TO PAY IT FORWARD." - RANDY PAUSCH

TSO is seeking volunteers for tabling, speaking and ceremonial events throughout our community.

Please contact Janet Ocasio at janetmocasio@gmail.com for details.

Training is available.



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COVID-19 INFORMATION RESOURCES

Every day brings a better understanding and information about COVID-19, especially for our special community of recipients, caregivers, and families.

You can easily keep yourself informed about COVID-19 and how it applies to your particular situation through government websites, state sites, and your transplant centers.

Of course, there are still unknown questions about immunity, reinfection, and, very importantly, vaccines for transplant recipients, but answers to these questions should happen. Of course, as soon as TSO learns about these answers, we'll let you know through Facebook, email, and our website.

If you would like specific information sources, please let us know and we'll be happy to help find the information you need.

POETRY CORNER

The Gift

*It is a precious gift bestowed on all
No diamond, lands, or gifts of gold
Can place a price or be as bold
As to extol its valued worth
For it is given to all at birth.*

*No fathomed price, no cost too great
Should make us leap and leave its
bounds
Although the here and after offers hope
That life, unfinished, carries on.*

*The irony of this curious state
Is that a power rules its fate.
Its unseen nature stirs the doubts
But we carry on amidst the clouds
Believing the promise in trust and
hope.*

*We carry on as we plan and dream
We reach for stars beyond our reach
We dream, we yearn, we dare to preach
So precious is this gift called life.
So live, succeed, fail, and be bested.*

*The dream is vast, the hope is endless.
It lives in art, in music, science,
In invention and in dreams
But flourishes most when we embrace
When kindness and love guide our
plans.
It lives in the promise that tomorrow
will come
Always in the hope that tomorrow will
come.*

*Written by: Janet M. Ocasio
August 15, 2020*

TARA

By: Mary H. Wu

Tara (Madden) McKeegan was born in the Bronx, NY on March 26, 1974. She was born with Cystic Fibrosis, but never let this illness stop her. On the contrary, it jumpstarted her on an amazing life journey of touching countless lives with her easy and friendly demeanor and natural God-given gift in connecting and advocating for herself and others.

Tara grew up in Rockland County, NY with her parents and three younger sisters; She was the eldest. Growing up, Tara loved keeping active and participated in such sports as Cross Country Running and Soccer. Tara earned a Bachelor's Degree at Fairfield University in Connecticut. She worked in Public Relations as a Senior Vice President at Bratskeir & Company in New York, NY. In Tara's personal life, she met her husband Raymond McKeegan through a good friend and they married in 2009. Tara was also extremely close to her family and especially her nieces and nephew who claimed she was "The World's Best Aunt."



Tara's health steadily declined, which required a double-lung transplant. At Duke University in North Carolina and on November 18, 2014, Tara received her life-saving double lung transplant. Both Tara and her husband reached out to the donor family, but did not hear back yet. Tara became an ardent advocate for organ, eye, and tissue donation and was greatly involved with registry events, public speaking, and volunteer activities with such transplant organizations as Transplant Support Organization and Rockland Organ Donation Alliance.

Tara was always an avid traveler. To celebrate the 5th anniversary of her lung transplant and honor her organ donor and their family, Tara and Raymond traveled to and fully basked in the glories of the Grand Canyon.

In roughly the middle of April 2020, word spread that Tara was fighting COVID-19. This upsetting news went viral on social media and beyond, and one simple request was made for Tara: "Pray for Tara."

On April 29, 2020 at the age of 46-years-old, Tara died after a fierce fight with COVID-19.

Sometimes, the most profound people and the best relationships sneak up on you and grow on you when you least expect it. It is only when that person is no longer there and in the worst times that you realize the sacred significance of that person and relationship. This is how it was with my friend Tara.

To quote her surviving husband Raymond McKeegan, "Tara was one of the good ones. She was always helping others. She was taken far too early."

Tara, we miss. We love you. Breathe easy and Rest in Peace.

JEN BENSON JOINS TSO BOARD

TSO was very happy to welcome its newest board member, Jen Benson. Jen is a five year out simultaneous kidney/pancreas transplant recipient from NYP/Columbia. And since then, Jen has committed herself to the cause of spreading the knowledge about registration and transplantation.

Jen has been very active in any number of activities. She participates in mentoring programs with the national kidney foundation; she is a member of the board of donor-to-donor, a Connecticut-based organization that helps living donors; and she is on the transplant council board for NYP/Columbia. Most recently, Jen has started an organization called Transplant Journey (www.transplantjourney.org) to provide a complete package of mentoring and information services to transplant recipients, whether pre-transplant or post-transplant, caregivers and families. Check out her website for more information.

We are very fortunate to have Jen join TSO with her passion and knowledge.

Continuous distribution of solid organs

For several years, UNOS has undertaken to improve organ allocation and distribution to make sure that transplantation occurs without regard to geographic barriers. Major improvements in reducing transportation times have allowed for a much broader placement of organs without regard to city, state, or any geographic hindrance. This has allowed UNOS to procure and send organs almost anywhere in the continental United States and make sure it is transplanted to the most medically needy waiting recipient.

To date, UNOS has created policies that have widened the distribution circle between donor hospital and transplant center. Improvements in distribution have led to policies changes for kidney, pancreas, heart, and lung transplantation.

After more years of study, UNOS has released a new study for public comment that includes geographic considerations as just one factor in the distribution decision. This study is called continuous distribution.

According to UNOS, “Organs can be distributed to candidates using a statistical formula that combines important clinical factors, such as medical urgency and post-transplant survival, along with proximity to the donor location. Using this approach, all candidates would receive a composite allocation score, but there would be no absolute geographic boundary. Candidates who receive the highest score based on their combination of factors receive highest priority.”

UNOS recently created a public interest survey that allowed any interested party to participate in helping the appropriate UNOS committees formulate decisions on donor organ distribution. The results of this survey should be known sometime in the upcoming month or so.

UNOS ACTIVITIES

UNOS has maintained a very busy schedule to make sure that transplantation in the United States returns to pre-COVID levels. And in the past 60 days, many transplant centers are operating at or above transplantation activities attained in 2019, a record year for transplantation. **As of September 10, 2020, there have been more than 10,200 donors providing more than 22,000 transplants.**

In addition, UNOS has embarked on a very impressive list of research and development activities to bring important improvements to the transplantation processes managed at UNOS.

UNOS has several pilot projects involving adding GPS tracking devices to the transportation activities involved when bringing organs from a donor hospital to a transplant center. This will make sure that the transplant center is in the best state of readiness to begin the surgical procedures for a waiting recipient.

UNOS has also created new simulation models to help anticipate program changes that may be needed in the light of the COVID pandemic. This will allow UNOS to adapt resources to needed geographic areas.

UNOS is also in the middle of creating a paired liver exchange program, designed along the lines of the paired kidney donation programs that were created several years ago. This will be a program to pair one donor and one recipient.

Finally, UNOS is creating another simulation program to help transplant surgeons get trained on best practices to accept an organ offer, to determine why one center will accept an organ that another center won't accept.

All of these projects will allow UNOS to make sure that organs are recovered and distributed in the best possible manner to increase transplantation rates.

FEDERAL AND STATE ACTIVITIES ON BEHALF OF DONATION AND TRANSPLANTATION

The Health and Human Services Administration (HHS) made a major announcement this week with significant updates to the support of living donation. On September 20, 2020, HHS announced changes to the Final Rule of the Organ Procurement and Transplantation Network (OPTN-42CFR121) that increases financial support for living donors in 3 major areas. The announcement covers the areas of lost wages, child care expenses, and elder care expenses for the potential donor as well as individuals designated as accompanying the donor for travel and tests.

There will be much more news about this announcement in the upcoming weeks, but this is a major step forward to allowing kidney and liver waiting list pre-transplant recipients to find living donors willing to participate in the transplant.

LIVEONNY SERIES ON DIVERSITY IN THE WORLD OF TRANSPLANTATION

LiveOnNY undertook a major series of webinars in September, 2020, to examine diversity and discrimination in the field of transplantation. Led by Dr. Amy Friedman, Executive Vice-President and Chief Medical Officer for LiveOnNY, this series was an open and honest discussion of the issues surrounding minority access to transplantation. In the wake of society's turmoil with racial issues, these webinars were a refreshing discussion of the problem and the solutions that are available to bring fairness and equal access for all citizens.

There were a series of 3 meetings bringing together doctors, social service workers, legal scholars, and academic experts in the area of discrimination in the minority communities. Each webinar had more than 100 attendees listening to discussions of the issues and proposals to remedy the problems.

The sessions were recorded and instructions to access the recordings will be available in the near future.



TSO Transplant Support Organization

Participant Application:

New

Renewal

Please fill out this form and mail it with your tax-deductible contribution to:
TSO, 1335 Mace Avenue, Bronx, NY 10469

NAME(s): _____

Mailing Address: _____

Phone # - Daytime: _____ Evening: _____ Cell: _____

Email: _____

PERSONAL INFORMATION (optional)

Birth Date: _____ Sex: _____ Marital Status: _____

Occupation: _____

CANDIDATE / RECIPIENT INFORMATION – Please check appropriate description

Donor _____ Donor Family Member _____ Transplant Recipient _____ Transplant Candidate _____

Family Member _____ Interested Individual _____ Professional _____

Have you already had a transplant? Yes _____ No _____

Type of Transplant(s) _____

Date of Transplant _____

Where did you (will you) have your transplant? _____

PARTICIPANT CATEGORIES & SUGGESTED CONTRIBUTIONS

Regular (Transplant recipient, transplant candidate, family member, donor family)

Individual Participant \$25.00

Family Participant (2 or more members, same address) \$35.00

Professional \$25.00

Please consider a voluntary donation to help support TSO \$ _____