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TRANSPLANT SUPPORT ORGANIZATION

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



VOL. 26, ISSUE 1

WINTER, 2021

Message from the Co-Presidents

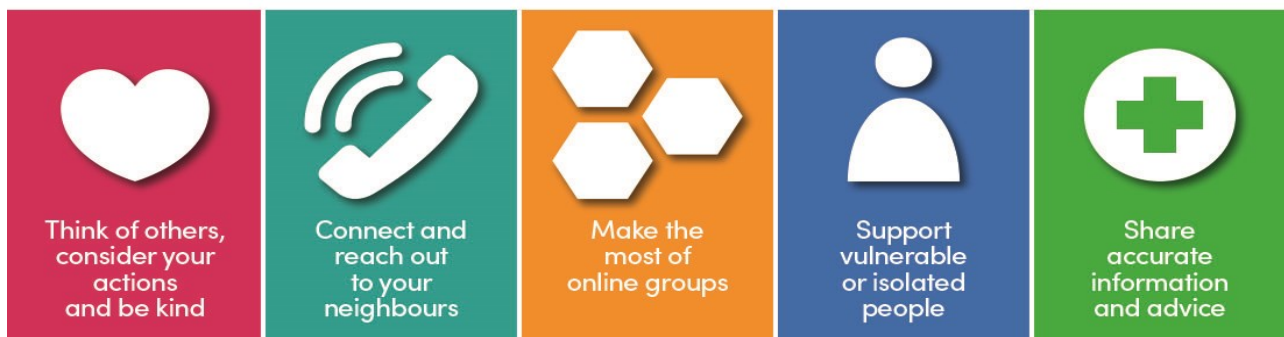
It's been a difficult year for all of us, there is no doubt of that. Social distancing from family and friends, staying safe and conscientious even with what has always been a simple trip to the pharmacy or grocery store, difficulty with doctor appointments, adjusting to new modes of communication via Zoom or other video conferencing facilities – a few of the worries that became a daily occurrence for almost one year now.

In some way, this pandemic has allowed all of us to demonstrate our strength and resilience. Quite possibly, the years of chronic illness or the onset of an acute life-threatening medical emergency – those events tested us, patient, caregiver, and family alike. The fact that all of you are still members of TSO points to that strength. You attend our meetings and you write those grassroots letters when needed.

Take heart from this strength. More and more people will receive the vaccine, immunity to this deadly virus will increase, restaurants and stores will open. Life will adjust to a new normal. But that's what all of us have done for years, we've adjusted to a new normal and made successes out of those changes.

TSO has adjusted to a normal, too. In fact, in some ways we've become better and stronger. TSO now reaches out to speakers from all over the country to bring their expertise to our meetings. Our attendance at these meetings has, in fact, increased. Do we miss being together in the same room? For sure. But let's focus on lemonade and not lemons, the glass half full not half empty. You know all the cliches. But they're good ones and TSO is in good shape.

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



TSO HOLIDAY PARTY

To TSO family and friends:

Thanks to all of you who turned out on December 16th for our holiday Zoom gathering.



We had poetry, songs, trivia contest, and the best costume competition. We hope you enjoyed our activities.

Once again, we wish all of you a very safe and healthy holiday season and a peaceful New Year. Let's look forward to 2021 with hope!

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**

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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PAY IT FORWARD

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

YEAR IN REVIEW

December, 2020

Dear friends,

What a year! What else can we say? But we're here and we're thankful for our health and well-being during this very difficult time.

In spite of a virtual quarantine for most of us since the 1st quarter of 2020, we've managed to stay healthy and safe and we've even accomplished a significant number of activities on behalf of donation and transplantation. Of course, we want to acknowledge the passing of Tara McKeegan and Anthony Bonelli, two long-time members and active volunteers with TSO.

First and foremost, we've stayed together as an organization. We've moved onto an internet based meeting platform away from our very lively monthly get-togethers in Greenburgh. But Zoom has turned out to have its advantages. Our attendance has increased significantly and we've brought in speakers from well outside our usual geographic boundaries.

We've continued to be involved and committed to legislative activities and issues on the state and national levels. These issues affect all of us: recipients, caregivers, and families. As a result of your continued support of our commitment, TSO has recently been recognized by the Verywell Health group for our advocacy activities on behalf of transplantation as one of the 8 best transplant support groups in 2020 (<https://www.verywellhealth.com/best-transplant-support-groups-4845597>).

With LiveOnNewYork, we participated in organ donor recognition day in October. We're finding very creative ways to keep organ donor registration alive and kicking!

We published our newsletters, in electronic form, to reach out to the several hundred readers we have on our mailing lists.

So, thank you! We hope you'll continue to stay connected to us. We've seen a drop in formal membership this past year, so we encourage you to become a dues-paying member of the TSO family. We can certainly take pride in being part of the LiveOnNewYork service area. LiveOnNewYork and its affiliated transplant centers wrote the national playbook to maintain donation and transplantation in the 1st and 2nd quarters of this year, when the pandemic was so serious in our area.

And while we're thanking you, we ask you to give your thanks to all of those people who kept things working in 2020: our doctors and medical staff, grocery store clerks, post office workers, all the public servants and private sector workers who toiled tirelessly this year in the most difficult of circumstances.

We'll continue with Zoom meetings into 2021. If you have suggestions for topics you'd like to hear about, please let us know. We're hoping we can get together for a family picnic in September, 2021, and our holiday get-together in December, 2021.

Thank you. From all of us at TSO to you, we wish you a happy, healthy, and safe 2021!

The Board of Directors, TSO

UPDATES FROM TSO

THE NEW AGE OF TSO

TSO plans to continue its meeting format using Zoom during 2021. This has been very helpful to us to hold our meetings, and very successful in recruiting new participants to our site

IMMUNOSUPPRESSION SEMINAR

On January 20, TSO hosted Dr. Nancy Krieger, the Medical Director of Talaris, at its monthly meeting. Dr. Krieger told us about the very successful activities that Talaris is doing to create long-term successes removing transplant recipients from immunosuppression regimens in as short a time as one year post-transplant.

Right now, the Talaris studies only involve recipients who have received a kidney from a living donor. But all of us have high hopes that the success of this program will be extended to all types of transplants, from living and deceased donors.

VACCINE WEBINAR - 1-26-2021

On January 26th, A very important webinar was held to discuss COVID-19 vaccines for transplant recipients. There is more information about this webinar in this newsletter

Please go to the following website for more information:

<https://www.covid19transplantresource.org/covid-19-vaccine-webinar>

2021 MEETINGS

TSO is still planning its full-year complement of meetings for members. We are always interested in hearing about the topics that interest you, so please let us know.

HARDCOPY DISTRIBUTION

TSO suspended its production and distribution of hard copy versions of its newsletter throughout 2020. However, hardcopy distribution should be reinstated in 2021.

If you know of a transplant center or medical practitioner office that could benefit from receiving our newsletter, send us a note at email4tso@gmail.com.

MEMBERSHIP DRIVE

Our membership drive will begin in a few weeks with letters going out asking you to join TSO with your dues payment. TSO will continue to offer its resources free of charge, but your dues help us pay for our efforts. Please consider sending us your membership dues when you receive our letter.

TSO SCHOLARSHIPS...from Len Andrew

Each academic year a high school senior has the opportunity to apply for a \$2,000 scholarship. TSO created the scholarship to honor the memory of deceased members and to promote the importance of organ, eye and tissue donor awareness through a community service project. High school students are asked the question of donation when applying for a Learner's Permit/ Driver's License. We believe the concept of donation is a timely and relevant topic for them.

Applicants must be high school seniors residing in the Bronx, Dutchess, Orange, Rockland, Putnam or Westchester Counties. They must show they have developed or participated in an educational or public service initiative related to organ, eye, or tissue awareness. Two letters of recommendation are required, one from a school faculty member and the other from a non-relative outside of school.

Applications must be submitted by June 1.

Find the application at <https://www.transplantsupport.org/scholarship-info>

 <p>BE A HIGH SCHOOL SENIOR</p>	 <p>DEVELOPED OR PARTICIPATED IN AN EDUCATIONAL OR PUBLIC SERVICE INITIATIVE RELATED TO ORGAN, EYE OR TISSUE DONOR AWARENESS. FOR EXAMPLES, GO TO HERE</p>
 <p>RESIDE IN BRONX, DUTCHESS, ORANGE, PUTNAM, ROCKLAND OR WESTCHESTER COUNTIES</p>	 <p>PROVIDE TWO LETTERS OF RECOMMENDATION, ONE FROM A SCHOOL FACULTY MEMBER AND THE OTHER FROM A NON-RELATIVE OUTSIDE SCHOOL</p>

MEMBER ACTIVITIES

Hospital letter writing

In late 2020, Scott Wohl from LiveOnNY sent out a request to the transplant community to write notes of appreciation and thank yous to donor center and transplant center staff.

We want to thank all of the TSO members and the members of many other support groups in our service area who responded to this request and demonstrated our very grateful thanks to the medical community for its tireless effort in 2020 in the face of unprecedented difficulties and challenges.

Our friend and long-time member of TSO, Pat Tomasulo, was recently featured in a front page article from her local neighborhood newspaper. Pat was eloquent and passionate in her discussion of organ, eye, and tissue donation.

Please check out the full story at the following:

<https://parkchestertimes.com/new-york-state-ranks-last-in-the-nation-in-percent-of-residents-registered-as-organ-donors>

COVID MEMORIAL

A transplant friend of Jen Benson's told Jen about a Covid memorial at Belmar Beach, New Jersey, that honors her sister and many others who passed away after contracting Covid.

Recently, Jen had a chance to visit the memorial and added a memorial rock for our beloved TSO member, Tara McKeegan. We've included two pictures for you: one of the entire memorial and one closeup of the rock in memory of Tara. The memorial is located at the beach entrance at 3rd Avenue and Ocean Avenue, Belmar Beach, NJ.



TSO SUPPORT FOR REGISTRATION PORTALS

TSO has always undertaken its activities on behalf of donor registration very seriously and very successfully. Even though hunkering down at home has made it impossible to participate in registration drives right now, there is still much that we can do to promote donor registration in New York State.

Donate Life New York State has put a lot of effort in recent years to creating registration portals. Enterprises and organizations can put the registration web link on any manner of websites, and those groups have created a portal for donor registration.

So all it takes now is for all of us to imagine websites where the registration link can be added. Former employers, doctor offices, clinics, charities – these are all viable sites for the link. Donate Life New York State has created an easy-to-use process for any organization that wants to put the portal link on its website.

Please contact Ike Copperman at irajay2004@gmail.com for more info.

Poetry Corner

A Special Hero, A Special Friend

*He rushes in...His white coat follows.
Concern is etched upon his face
His movements quick...He's like a whirlwind.
He wears his worry with his grace.
No one will die on his watch.
Not on this night... not in this fight.*

*She moans and bleeds, her life receding.
As sickness seeks to win tonight
She cannot see his valiant efforts.
But through the night he is at war
As family waits in helpless pleading
Surrendering faith to him once more.*

*His name is Wolf...predator...relentless
warrior.
He'll not relent this fight for life.
For his convictions provide the courage
No, no one will die on his watch tonight.
The night is long but it does pass and
settles into morning.
A quiet grace descends throughout.
They breathe and gather with relief
Witnesses of grace and determination
Today there will be no mourning.*

*With victory declared a friendship rises
As Wolf and patient move past this crisis
To more tomorrows with lessons learned
They will teach others what they have learned.
That warriors with compassion are more than
heroes.
They are our angels and our lifelong friends.*

*Written by Janet M. Ocasio
February 7, 2021*

*In August of 1998 I almost lost my life to Liver Disease. I had been on a waiting list for a transplant for 13 years and my condition had progressively deteriorated. Dr. David Wolf, my Hepatologist of 5 years responded immediately and remained at my bedside for hours, refusing to leave the hospital. Through his valiant efforts my varices bleeding was controlled, and I eventually regained consciousness. To this day I credit him for saving my life. I was only 46 years old and I had 3 children at the time, all in school. Now 22 years later, Dr. Wolf he is still my Hepatologist, and I like to think my friend as well. We have done many workshops and presentations about organ donation and transplant. I will always be thankful that he was my doctor.

The following poem is written by our TSO member and volunteer Mary Wu

Grit

*Times are Tough
Reality Sucks
We've had it rough
Enough is Enough
I keep saying
It can't get any worse
But it feels like an unending
curse
I am being proven wrong
I long for the days before
these days
I keep praying
Better days ahead
But, please do, tell the truth
In all of our heads
Is this sort of dread
Of what lies ahead
For the only certainty
Is the uncertainty*

*While the world keeps on
spinning
We are all falling
We see what we want to see
Those public surface
successes
Blind to private struggles
And to all our hidden pains
We gain and get a thick
skin
We lose a lot for short-lived
wins
Oh, but, those cheaters,
haters, and liars
Fuel to my fire
Burns deep in my belly
Light in my eyes
I cannot disguise
Every fight I fought*

*Every lesson I learned
Everything life taught
Every challenge I met
None were my choice
But without any regrets
I choose to accept
Without explanation
Daunting Determination
Brave and Bold
There it is
So brightly lit
It is called hope
And, still, despite all of this
I still got my grit*

Written by: Mary Wu

Secondhand Heart and the Fish that Got Away

From David Verge

I don't know how it ever started but I seem to be the perfect prey for a nickname. It's a kid thing, right? Or like a gangster thing. Lefty Larry, Crooked Finger Jack, Baby Cakes or Hitchhiker Joe. Yeah yeah, American Indians do it too, Trip-On-Bird, Buffalo Turd and Sleep-All-Day. I must admit that I've been called the latter. I've had the typical young age ones, Red was the most common for me but now since that sunset hair has faded and gone, it has been replaced with Egghead, well at least it's not potato head. And since this is NY, it doesn't work alone. It needs that prefix with an attitude. "Yo" or "Hey Yo" plus the nickname and sometimes with a 'dude' after it. Obligatory. The local Hispanics must think we're crazy yelling "Yo" all of the time.

Since my heart transplant, it seems like my friends have been on the dumbdumb steroids with the name calling. When I got 'the call' and was in the hospital, they all came and easily took over the waiting area. I heard later that they had a contest for the best one. Dying Dave came first and they all laughed nervously in fear. They became quiet and fidgety after that one and they just sat there in contemplation. Unease and uncertainty were in the air. After the second hour of waiting one of them said Praying Dave, then an hour later it was Praying Dave Fav and finally after 5 hours it was Save Praying Dave Fav.

I have no idea how they snuck into the room, but when I woke, there they were, all circled around my bed. Right away it started. Yo Dripping Dilaudid Dave, nice tubes dude...yo. IV bedbaldhead, Pressuredrop, handrail hostage and on and on. Finally they left the room and when they returned they said in unison "Secondhand Heart." But of course they couldn't control themselves. A few weeks later when walking down the street I heard them giggle and yell 'Yo Handmedown.' The Hispanics all stopped and stared.

Then Covid came to town and we rarely saw each other. They knew of my condition and respected that; a far cry from the maskless warriors of death all around. I was homebound and my only real excitement and adventure was driving; there I was safe. It was a new feeling; the roads were completely empty. I was up at dawn every day to drive Lourdes to the hospital where she works and afterwards I would drive. One day I dropped her off and spent all day driving back and forth on the new Tappan Zee Cuomo Bridge. You know, safety check, looking for cracks and feeling the bounce. After that I wised up and bought an EZ Pass. Once I went to Maine to buy some lobsters for dinner and I barely made it back in time to pick up Lourdes at the end of her shift. When it dawned on me that my tires treads were no more I stopped the excursions. What was left? Gym and swimming were out. Barroom darts and The Fred Astaire dancing school were closed. After much thought, I figured that fishing was a good solitary sport.

But it got away

A Hospitalization in the Days of COVID-19

It's New Year's Eve and I arrive, in my own car at the emergency room. I don't call my daughter since I know by now that she would not be permitted to enter with me. I am immediately struck by the differences in the hospital environ. I remember a center of much activity instead I am confronted with a near empty parking lot. Few people mill about as I make my way from my car towards the entrance. Where are the people, I wonder, I can't tell if its open noting darkened doorways? It's New Year's Eve, sadly a statistically busy time for emergency rooms, the area should be bustling with activity, but in the days of COVID-19 it is not.

As I enter the ER waiting room, I am struck by how eerily empty it is and beyond that I am struck by how seats are separated, turned in different directions. Plexiglass forms a barrier between staff and the waiting room and beyond the ER the halls seem dark and deserted. I follow arrows which are placed on the floor and signs marking off 6-foot intervals. I walk up to the plexiglass barrier at a reception counter and am greeted by a registration staff member who wears a plastic face shield, gloves, and a mask. Over her clothing she wears a paper gown. I hesitate not sensing a smile until she looks up at me and the registration process begins. At least the paperwork is familiar, sign here, sign there, take a seat. I wait for about 15 minutes choosing an isolated seat in an isolated waiting room when I am approached by a shield wearing, mask wearing, paper gowned and glove wearing nurse who offers me a seat in a wheelchair. I am ushered to a room and I note corridors that are sealed with plastic sheets and taped shut and I don't have to ask where these hallways lead to, I know.

I am both relieved by the precautions employed by the hospital and bothered by them. It is striking that we can no longer look at each other, that we are defensive to an extreme about infection and sanitation. It creates a barrier between us, and "others" and the others are now everyone.

I am admitted to the hospital, as I expected but not before I pass a COVID-19 test after which I am quicky whisked away to my hospital room to begin my treatment for what I already knew I had, extremely low Sodium also known as Hyponatremia, a recurrent problem.

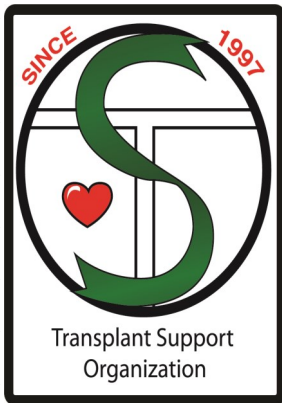
As I travel towards my room, I take note of the surrounding areas and I am stuck by the many measures of isolation which permeate the corridors and rooms. Some are taped off and dark indicating no entry. Arrows point the way and the 6-foot distance markers are everywhere. Sanitation stations are clearly visible, and it strikes me that they seem to sparkle in welcome, the new celebrities in our super sanitized world.

I am made comfortable in my room by nurses wearing the sanitized uniform of COVID-19, mask, shield, disposable garb, gloves. I consider their courage and dedication as I think about the risks that they take everyday to care for the ill, I respect. I spent 2 days in my very sterile environment and as I feel better, I am given permission to walk in the hallways but of course I must follow the arrows and the 6-foot markers. As I stroll, I am struck by the COVID-19 reminders and precautions which are everywhere like Christmas decorations. I am also struck by the isolation, and the desolation that I encounter. Many rooms are empty on this floor, and I note areas that are blocked lest someone like me wonder into them. I think about the patients who must be beyond the ropes ensconced in plastic sealed areas. I think about their suffering, that of their families, and that of the people who sacrifice as professionals to care for them. In my mind I sense a terrible darkness although the halls are lighted and bright. I do not understand why this has happened, why this Pandemic, why at this time, why all this suffering. I want to go home to my small cocoon of safety where I too am isolated and protected, I hope. But I know that I will never forget these impressions, that I shouldn't forget these impressions. This is our world now, this will pass, but how great the price has been.

Written by: Janet M. Ocasio, January 23, 2021

Happy Re-birthday to You!

Our best wishes to all our TSO friends and participants who celebrate re-birthdays in the first half of the year January through June! Our sincerest wishes for many more happy and healthy years to come!



Joining TSO is an important part of keeping us involved with you and with the entire transplant community. Our meetings, our events, and our legislative efforts come from your support.

Your dues allow TSO to continue doing the important work of education, support, public policy advocacy, and outreach which is so important to us all. Your dues are our main source of financial support. This is your organization, we need your dues to continue the work.

Please use the membership form found on page 11 to join and return the completed form with your check made payable to TSO.



If you have sent in your membership payment, thank you very much!

If you have not sent it in yet, please consider doing it today.



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 \$ _____