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TRANSPLANT SUPPORT ORGANIZATION

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



VOL. 24, ISSUE 3

FALL, 2019

Next Meeting Date - November 20, 2019

Greenburgh Health Center - 295 Knollwood Road - White Plains, NY 10607



TSO HOLIDAY PARTY

Are you ready to start the holiday season on a very festive note?

TSO's 2019 Holiday Party takes place on Tuesday, December 3, 2019. We're going to be at Sam's of Gedney Way in White Plains and we're looking forward to seeing all of you.

Mark it down on your calendars and plan to come out and visit with all of your TSO friends and family.

For more information call 212-222-8386.



Transplant Support Organization

cordially invites you, your family and friends
to celebrate the joy of the season at our

Annual Celebration of Life Holiday Gathering

at

Sam's of Gedney Way
50 Gedney Way, White Plains, NY 10605

Tuesday, December 3, 2019

6:00 p.m. to 10:00 p.m.

Full Buffet Dinner, Raffle, Lots of Fun, Cash Bar Available

Name _____

Please reserve _____ seats at \$70.00 per person
((\$85.00 per person when paying at the door))

Total amount enclosed \$ _____

I am unable to attend but enclosed is a contribution of \$ _____

Please make checks payable to TSO and mail to:
TSO, 1335 Mace Avenue, Bronx, NY 10469 ATTN: Gerard Marinaccio
or use the enclosed self-addressed envelope for your convenience
For information call: Ira Copperman - (212) 222-8386
Space is limited - Please RSVP by November 26, 2019

Transplant Support Organization meetings are held at 7 p.m. on the third Wednesday of the month (with some exceptions) at

**Greenburgh Health Center
295 Knollwood Road, White Plains, NY 10607**

www.greenburghhealthcenter.com



For directions to our meeting, donor registration form, and further 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

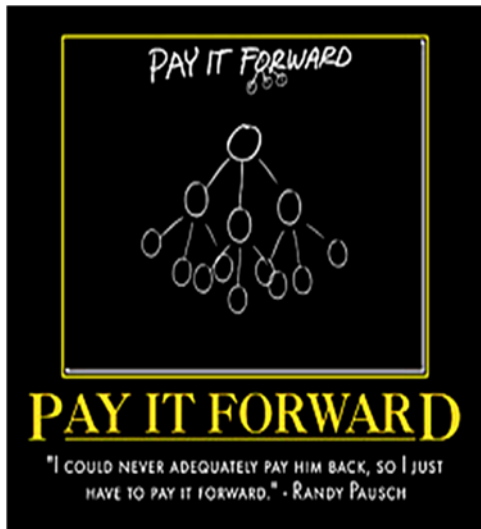
We are also on Facebook. Check us out for information and updates.

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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TSO Meetings - Past and Future

Our meetings are held on the third Wednesday of every month starting at 7:00 p.m. The location is The Greenburgh Health Center Community Room, 295 Knollwood Road, White Plains, NY, 10607.

Check out our website (www.transplantsupport.org) or send your email address to us (email4tso@gmail.com) to add your name to our distribution list.

Past Meetings

July, 2019 – No meeting

August 21, 2019 – Joint TSO/Westchester Medical Center Meeting - “Transplanting Hope”, an inspiring documentary about organ donation

September 14, 2019 – TSO Family Picnic
Sleepy Hollow, NY

October 16, 2019 – Dr. Rosemary Soave, Immunologist, NYP-Weill Cornell -
Infectious diseases
THIS MEETING WAS CANCELLED AND WILL BE RESCHEDULED FOR 2020.

Upcoming Meetings

November 20, 2019 – Lauren Stewart, Veloxis Pharmaceuticals -
Patient experiences with new immunosuppressives

December 3, 2019 – TSO Holiday Party -
See front page for all the details

January, 2020 – No meeting

Please send your suggestions for topics and speakers to email4tso@gmail.com.



*Help Support TSO and Shop Using
Amazon Smile*



**New Amazon
Program Enables
Shoppers to Easily
Donate to Their
Favorite Nonprofits**

You can now help support TSO when you shop using Amazon Smile. It's simple – just sign in to www.smile.amazon.com and choose Transplant Support Organization Bronx, NY as the charity that you would like to support. The Amazon Smile Foundation will then donate 0.5% of all eligible purchases to TSO!

Co-Presidents' Corner

It's quite hard to believe but we're now planning for our 2019 Holiday Party on December 3rd. Here's a time for all of us to get together with friends and family and enjoy a very festive time together at Sam's of Gedney Way in White Plains. Watch your mail, email or front page of this newsletter for all the details.

It's been a very productive year for TSO. We've lent our voice to state and national issues to improve the climate for organ donation, waiting list recipients, and those of us who have received a gift through a transplant. TSO has been an active player in maintaining our access to prescription drug plans, improving reimbursement of costs for living donors, changing the waiting list dynamics for pre-transplant liver recipients, and increasing the numbers of registrations on our state donor registry. All of you have made the contribution of your time and effort and support to helping TSO advance its legacy of giving.

We look forward to continue to have your participation in all of our events and activities.

Thank you!

How to find the name of your US Senator or House Member

One of the most important activities we can do is to lobby for change. Our collective voice, through grassroots efforts, makes an important contribution during the legislative process.

When you want to send an email or write a letter, you can very easily find the name of your United States Senator or Congress person.

For the House of Representatives, go to the following website: <https://www.house.gov/>

Once you're on that website, you'll see a box where you enter your zip code; then the name of your representative will appear. There will also be a link to your representative's website.

For your Senators, go to the following website: <https://www.senate.gov/senators/index.htm>

That will bring you to a page that lists all of the Senators. Enter your state in the appropriate box, and your two Senators will show up. Click on either name, and you will be brought to the Senator's website.

Your State Representatives

It's very easy to get the information you may need to call, write, or even visit the offices of your state assembly member or state senator.

For your assembly member, go to the following website: <https://nyassembly.gov/mem/search/>

Put in your home street address and zip code, click on the search button, and the name of your assembly representative will show up.

For state senators, go to the following website: <https://www.nysenate.gov/find-my-senator>

Enter your address information.

Living Kidney Donation through the National Kidney Registry (NKR)

The number of people on the UNOS waiting list for kidneys year after year represents more than 80% of all the people listed for all organs. So finding ways to perform transplants for those waiting is a challenge because there aren't enough kidney donors.

In 1954, a living donation for kidneys started the modern era of transplantation. The first successful kidney transplant was from a living donor, Ronald Herrick, at the age of 24, to his twin brother, Richard, in December, 1954, at Peter Bent Brigham Hospital. Richard lived for 8 more years after receiving a transplant, and Ronald lived until he was almost 80 years old.

So the promise of living kidney donation has been available for a long time. In fact, in 2018 there were almost 6,500 living kidney donors in the United States, 40% of all kidney donations.

In recent years, there have been significant efforts to encourage living donation, coming from several organizations. One of the organizations that has lead these efforts is the National Kidney Registry, started by Garet Hil. Garet donated a kidney in 2015 to provide a 'voucher' for his daughter who received a kidney transplant 12 years ago. Both Garet and his wife, Jan, were incompatible and could not donate to their daughter 12 years ago when she was on dialysis; now his organization helps recipients find well-match compatible living donors.

NKR is an organization where people in need of a kidney transplant can enroll in their paired exchange program through a participating transplant center and NKR will work on finding a well-matched compatible donor. NKR offers a full set of protections for living kidney donors to make sure the focus is on the donation and not on the concerns that accompany a person's desire to donate a kidney. Believe it or not, there are significant disincentives that make it difficult for someone to donate a kidney:

- ◆ Most employers don't compensate donors for lost wages;
- ◆ Travel expenses and lodging, to and from the transplant center, are generally not paid for by insurance or the transplant center;
- ◆ Although very rare, some insurance companies may cancel coverage or raise health insurance premiums after a donor donates a kidney;
- ◆ There may be post-surgical complications that are not covered by the patient's insurance or the transplant center;
- ◆ Sometimes post-surgical complications require the donor to take unpaid leave from work; requiring the donor to take unpaid leave from work;
- ◆ Finally, there is the concern donors have that someone in his or her family may need a kidney in the future, and the donor won't be able to provide a kidney for his or her loved one.

NKR has addressed these issues through its comprehensive Donor Shield program and provides the Donor Shield protections for every donor who participates in an NKR swap. Donor Shield includes the following protections:

1. Lost Wage Reimbursement up to 4 weeks
2. Travel/Lodging Reimbursement up to \$2,000
3. Donation Life Insurance with \$500,000 principle amount
4. Donation Disability Insurance up to \$1,500/ week for up to 52 weeks
5. Legal Support for unlawful termination and health insurance issues
6. Coverage for Uncovered Complications related to donation surgery

With this kind of comprehensive coverage, NKR seeks to eliminate disincentives that prevent many people from becoming living kidney donors. For more information on NKR, visit its website at www.kidneyregistry.org.

Guidelines for Immune-compromised Travelers

Do you have travel plans coming up during the next few months? The Centers for Disease Control and Prevention (CDC) maintains an excellent website for travelers, giving them the latest information and warnings about traveling to regions or countries with or without children or other family members. There's a special section for immune-compromised travelers, like transplant recipients, that's very helpful. Check out the following site: <https://wwwnc.cdc.gov/travel>

Enrollment Day

October 10th marked the annual Enrollment Day in the New York Region. Although TSO did not organize its own team this year, we did something very special acknowledging Enrollment Day and honoring a very good friend to organ donation and to TSO. TSO participated in the Northern Westchester Hospital's commemoration to the hospital's retiring CEO, Joel Seligman. In fact, TSO played a very important part in this special event dedicated to Joel and recognizing Enrollment Day.

The Hospital set up its lobby with photos and information regarding organ donation. A sign-up table was available and staffed by hospital volunteers and TSO's Carolyn Robinson and William Flynn, two avid volunteers. A large poster was on display in the lobby featuring TSO's Janet Ocasio with her story and a recent poem which was written regarding the power of organ donation to save lives.

A ceremony was held in honor of this event and Joel's retirement. Speakers included, Helen Irving, CEO of LiveOnNY, Assemblyman Buchwald, Mayor Picinich and Janet Ocasio. Joel was presented with a plaque for his longstanding commitment to the cause of organ donation awareness and thanking him for his support over many, many years both at Northern Westchester Hospital and at Mt. Sinai Medical Center. TSO thanks Joel Seligman for his support over many years and allowing us to participate in numerous events, including past Enrollment Day events. We wish him the best on his retirement and look forward to hearing from him as he enters this well earned phase of his life. We will miss him.

Part D Update

The Partnership for Part D Access has not rested, even since the announcement from Medicare that they would not change the status of the 6 protected classes (6PC), allowing patients unrestricted coverage to the prescription drug regimens they follow.

So what does that mean about keeping busy, if Medicare has taken that action? It turns out that the Partnership has detected some objection to the report that was circulated in Congress that supported continuing the 6PC. This was a privately-funded report from an organization called Avalere; the Congressional pushback is that it is biased and one-sided (not even close to being true, but facts are disputable in Washington these days).

So the Partnership is reaching out to members of Congress to push for a government-sponsored study from the Government Accounting Office (GAO). A report supporting the 6PC from a government agency will quiet many of the Congressional critics who have loud voices.

So that's the latest on the Partnership and 6 PC. Please let us know if you have any questions.

TSO at Northern Westchester Hospital, 10/10/2019

TSO was honored to participate in a donor enrollment day program at Northern Westchester Hospital on Thursday, October 10, 2019.

The featured event at the hospital was honoring Joel Seligman, CEO at NWH, for his 19 years of service as he steps down from his position.

Helen Irving, CEO of LiveOnNY, made some remarks about her long-time association with Mr. Seligman. She then presented a plaque from LiveOnNY and TSO to Mr. Seligman, recognizing his years of service and his commitment to organ, eye, and tissue donation.

The mayor of Mt. Kisco, Gina Picinich, offered her remarks, followed by Dave Buchwald, New York State Assemblyman from Mt. Kisco. Finally, Janet Ocasio spoke about her transplant journey and her long-term association with NWH. To commemorate the occasion, she also read a poem she had written about the gift of life of organ donation. Janet's poem can be found in this newsletter.

Carolyn Robinson and Bill Flynn were at the table registering hospital visitors to be organ donors. Glenda Daggert and Ike Copperman also represented TSO for this event.

Poetry Corner

Donor

*A priceless gift adorns you
And gives you hope unquestioned
A donor blessed in giving
A story told, the gifts now mentioned
A silent giver rises
Now joining in the heavens
With others who have understood
That life is hope realized
We all have heard refrains
That speak of brother's keepers
For within us lies the power
To rescue and to save*

*To give whatever has been needed
The choice seems serious and grave
But look past thoughts that drive you
And recognize the truth
The gift of life
Is yours to make
The choice a simple question
To give what you no longer need
As heaven calls you to your sleep.*

Written by: Janet M. Ocasio

The following poem, "Little Girl", written by our TSO member and volunteer Mary Wu, is a poem she wrote about her second organ donor who was only 4 years old when she died.

Little Girl

*I saw you
In my sleep
In my dreams
Last night
Your smile so bright
In the glowing light
You were so happy
In a dress so pretty
Patterns of swirls
You twirled
You had the whole world
You were just a little girl
You are still just a little girl
Your small hand
Reached out
Opened up
Like whispering wings
There are many things
I never did understand
I never will understand
Yet all my doubts
Melt into yesterday
Float and Fall away
I hold your hand tight
You tell me it will be alright
You say I will be alright*

*I tell you that you will be
alright
If I knew then
What I know now
I would still do it all over
again
I won't tell you anything
I will let you live everything
All your adventures
Savor your surprises
Laugh and cry
Live in the lows and highs
Heart break and beat
Until we someday meet
And you are all grown up
And I have grown old
I knew you
As only a little girl
With the whole world
Before you then
Before you now
Your life was cut short
I live with guilt
The life you could have had
The life you could have built
I build now*

*I have now
For now
I handle
I cradle
You with
A gentle
Loving care
I wish
So much for you
My sweet dear
What I would do
To have you here
I still see you
But only in my dreams
But only in my sleep
You are still
A little girl
Just a little girl
Only a little girl
Always to me*

Written by: Mary Wu

Why Volunteer by David Verge, Heart Recipient

TSO stands for Transplant Support Organization and they do just that. I joined the group 2-3 months out of transplant; hell, maybe the first month. The group has well exceeded my expectations. Each meeting has a guest speaker, I mean Pros; Doctors of every field, Cardiac, Pulmonary, Dermatology. Transplant Coordinators, Social Workers, CEO's of DonateLifeNY, LiveOnNY, movies, scholarships and even parties and picnics. It is continuing transplant education with enough credits to earn a degree in Transplant Teaching. We are learning for ourselves and have gained the ability to spread this knowledge to promote understanding of transplantation and organ donation. The reason 'we' are even in that room is because of organ donation.

I write this with one purpose and that is to get more people to become organ donors. The only way to do that is with more volunteers. That is where the 'we' comes into the picture. We are the best recruiters or the common word here is volunteers. We volunteer to share our experiences and to register people to become Organ Donors. We educate. We use our second chance for 'the cause' and oh, what a sweet cause it is.

WE, being anyone involved in the recycling movement, not only come out to get people to sign up to become donors, it goes beyond that, and we are given a platform to do this by LiveOnNY. They work for us in obtaining an organ and we got a super big one-time payment. Now we work for them for free; it is a win-win. It's in the perpetual motion that makes it work from donor to plane to helipad to organ ambulance to hospital to body. And back to us. We work to make it happen.

The thing is, "why not volunteer?" Put on your sailing shoes and give it a try; if it's not for you, so be it. I know that I owe it to my donor; you could say that I made that promise over and over while confined to a hospital bed, staring at 10 different IV bags with all sorts of annoying beeping sounds with no turn off switch in sight and not enough dilaudid to help the pain but enough to put my mind in the dust. Some of you can relate. We all have our incredible stories of bravery and misfortune and yet we all stayed alive long enough to obtain an organ from someone who was selfless enough to sign that donor card, that DMV form, or who had a loved one who made the difficult choice. They made the right choice.

Life is a beautiful thing...

TSO Volunteers

TSO Volunteers were very busy this summer and fall. From Brewster to Yonkers, our volunteers attended a number of events. They did tabling, public speaking, outreach, whatever the task required. TSO documented these events in photos which you can view on our website, facebook or our new Instagram page "TSO of Westchester." Our volunteers are the heart of our organization and this year families joined them and participated as well. TSO was represented at the Heartwalk, the Maria Ferrari Children's Expo, Blood drives, the Horse Show and the Yorktown Street Fair. This participation generated a large number of new organ donor enrollees who could potentially save hundreds of lives. And we had a great time. These events are fun, a great way to make new friends.

To all of the volunteers who worked at the events, to the volunteers who helped us to identify events and to connect with new sponsors, thank you! Your dedication and commitment to this cause is incredibly special. TSO will never forget all that you do.

If you are interested in volunteering please contact Janet Ocasio at www.gkjp@aol.com or email4tso@gmail.com.

From LiveOnNY for our newsletter...

Transplant Support Organization Joins LiveOnNY for Fifth Annual Organ Donor Enrollment Day

On October 10, TSO partnered with LiveOnNY for the fifth annual Organ Donor Enrollment Day and helped enroll approximately 2,500 New Yorkers as lifesaving organ donors.

Several TSO members participated and helped educate the community. Liver recipient Janet Ocasio spoke at Northern Westchester Hospital during an event honoring their retiring CEO, Joel Seligman, for helping to raise awareness about donation. She was joined by several members of TSO who looked on as she read a moving poem about how her transplant transformed her life.

Additionally, heart recipients Ricky Gongora and David Verge held an enrollment drive at the Yonkers Public Library. The pair had many meaningful conversations about the power of organ, eye and tissue donation. Their hard work led to the City of Yonkers winning the award for Most Enrollments by a Municipality.

In total, there were 150 locations and activations in the greater New York area. A dozen elected officials participated this year and Gov. Andrew Cuomo issued a statement about the power of organ donation. There were more than 100 social media mentions and 30 press stories about the day, including one by [NY1](#).

LiveOnNY was proud to once again partner with TSO on this important day. TSO has shown a deep commitment to raising awareness about the power of organ donation and LiveOnNY is honored to call it a partner.

How's New York Doing?

New York State is on track to exceed 2018 numbers for transplants, from both deceased and living donors for all solid organs, based on data from UNOS as of August 31, 2019.

And all of the New York metropolitan area transplant centers are on track to equal or exceed last year's results as well.

Thanks for this go to the tireless efforts of LiveOnNY and all of the donor hospitals in our region for their efforts on behalf of showing the good that comes from organ, eye, and tissue donation.

Transplant Resources on the Web

TSO has recently added a page to its website, www.transplantsupport.org, as a resource to find other websites connected to transplantation. There are links to organ-related sites, such as heart or liver; professional organizations; and the governing bodies over transplantation in the US.

We will be adding more and more references in the very near future.

If you have a particular website you've used, let us know and we'll add it to our list.

Happy Re-birthday to You!

Our best wishes to all our TSO friends and participants who celebrate re-birthdays in the second half of the year July through December! 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 \$ _____

TSO
Transplant Support Organization
1335 Mace Avenue
Bronx, NY 10469

NEXT MEETING: November 20, 2019

Transplant Support Organization's Mission

To help save lives by:

- *Providing* education relating to organ donation and transplantation;
- *Promoting* organ and tissue donation as an important social responsibility;
- *Giving* support to transplant candidates, recipients, their families and donor families;
- *Effectively* communicating to government bodies and the general public, the concerns and needs that affect the welfare of those individuals impacted by the transplant process.

