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TRANSPLANT SUPPORT ORGANIZATION

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



VOL. 19, ISSUE 4

FALL, 2014

Next Meeting Dates

10/15/2014

11/19/2014

Greenburgh Town Hall
177 Hillside Avenue
White Plains, NY 10607

Stop Homophobic Organ Donation Ban

Posted by Eavie Arntzen

Target: Margaret A. Hamburg Commissioner at the U.S. Food and Drug Administration

Goal: End homophobic ban on organ transplants from gay donors

Homophobic and baseless Food and Drug Administration FDA regulation refuses the donation of certain tissues from gay donors on top of their much-opposed ban on gay blood donation. Stigmatized ostensibly for the presence of HIV-ridden tissue, donations are regularly turned down from donors who tested negative for the virus. Extremely accurate HIV tests are conducted on all possible donors before any organs are harvested. In fact, modern tests are capable of detecting HIV from the moment it becomes infectious.

Despite so many safety screens, despite the fact that straight donors do not suffer the same injustice and despite the FDA's willingness to transplant a gay donor's heart and other organs, certain tissues are still discarded, against the donor's wishes. This was the case for Iowa teen A.J. Betts, who certified his wish for organ donation months before committing suicide—a reaction to insufferable bullying over his sexual orientation. According to the FDA, since Betts' mother was not able to prove whether the teen was sexually active, his eyes were refused for donation. However, his liver, kidneys, heart and lungs were all accepted and successfully transplanted.

The science to support the refusal of certain tissues or blood from HIV-negative donors simply does not exist and is blatantly homophobic. The ban on blood donation from a gay man is total—whatever his HIV status, while a man who had sex with an HIV-positive woman is only deferred from donation for a year.

Discrimination against sexual orientation is rampant enough in our society, but the stance of government-funded organizations furthering accepted homophobia baselessly is deplorable. The FDA is supposedly led by the scientific community and by factual study, yet insane bigotry against the last wish of a 16-year-old in his darkest hour to be a better human is allowed, unfounded.

Urge the FDA to end its ban on the transplant of certain tissues from gay donors unless factual evidence to support the refusal can be presented.

CONTINUED ON PG. 3

Transplant Support Organization meetings are held at 7 p.m. on the third Wednesday of the month (with some exceptions) at Greenburgh Town Hall, 177 Hillside Avenue, White Plains, NY 10607

Schedule for Monthly Meetings

7:00 p.m. — Social Time; 7:30-9:00 p.m.— Meeting and program for evening

October 15 – Dr. Vinay Nair, Interim Medical Director, Kidney Transplantation, Recanati Miller Transplant Institute, “*New UNOS Kidney Allocation System and New UNOS Pancreas Allocation System*”.

Future Meeting Agendas

November 19 – *Panel Discussion on “Religions’ Views of Organ and Tissue Transplantation”*. Rabbi Charles Sheer, Director, Cultural Competency Education at Westchester Medical Center; Dr. Mahjabeen Hassan, Board Certified Plastic surgeon, Senior Attending at Phelps Memorial and St John's Riverside, Co-Founder/ Board Member of Center for Jewish Christian Muslim Understanding, Founder/Board Member of American Muslim Women's Association; Rev. Dr. Robert J. Norris, Pastor of Our Lady of Mt. Carmel Church, Elmsford, NY and Living Kidney Donor; Pastor Paul Egensteiner, Emanuel Evangelical Lutheran Church, Pleasantville, New York.

December 8 – *TSO Holiday Party*, DoubleTree Hotel, Tarrytown, NY...see additional information elsewhere in this newsletter.

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

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:
Janet Ocasio - janetmocasio@gmail.com

The UNOS National Patient Waiting List

Candidates as of 3/30/2014

101,689	patients waiting for a kidney transplant.
15,677	patients waiting for a liver transplant.
1,185	patients waiting for a pancreas transplant.
2,049	patients waiting for a kidney-pancreas transplant.
255	patients waiting for an intestine transplant.
4,004	patients waiting for a heart transplant.
54	patients waiting for a heart-lung transplant.
1,637	patients waiting for a lung transplant.
123,814	TOTAL PATIENTS

Every 12 minutes a new name is added to the waiting list.

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LETTER FROM THE PRESIDENTS



Presidents' Letter – Fall, 2014

We're not quite sure we know what happened but the summer came and went like a flash!!!

It's always refreshing when all of you pitch in and rally on the important issues. And the topic of Part D payment for immunosuppressive drugs is of vital importance to all of us. As a result of your efforts, a task force has been formed with a lobbying firm in Washington to monitor efforts by the government to change the Part D compensation. There are several very important meetings to take place in the third quarter of 2014 including meetings with our Congressional members to maintain the focus on the Medicare coverage for our immunosuppressive pharmaceuticals.

Many of you participated in our regular monthly meetings since our last newsletter. In July and August, we met jointly with the transplant support group from Westchester Medical Center. We hosted a volunteer training session with the NYODN and the NY Blood Center and we co-led with social workers a support group for our participants.

So, let's tell you about our upcoming meetings and programs. We've scheduled several excellent meetings for October and November. There is more information about these meetings on page 2 of this newsletter.

Of course we have our holiday season party on Monday, December 8, 2014, at the DoubleTree Hilton in Tarrytown, NY. We hope you've already marked down the date on your calendars. There's always an opportunity for you to help us with items for our silent auction. The auction and the raffle are two of our most important fundraising activities for the entire year to further our mission and our activities.

As far as helping TSO, there's always a place for volunteer support through our many registration events. Janet Ocasio is again leading these activities, working with the New York Organ Donor Network and receiving requests from other groups asking us to participate. The demand for TSO participation in community events has increased as our organization has reached out to work cooperatively with a variety of health and social agencies. This community participation is important for TSO and we have received much support and recognition as a model community support and self-help organization. We can always use your help! Volunteer and make friends as you pay it forward by enrolling new organ donors and spread awareness about organ donation and transplantation. Contact Janet or TSO through our email (email4tso@gmail.com).

And speaking of supporting TSO, we've worked hard to maintain dues at a level that's not a burden for anyone. So please consider joining TSO; send in your enrollment form with your payment for the dues, if you haven't already become a member! Welcome to the TSO family.

Janet Ocasio and Ira Copperman
Co-Presidents, TSO

Stop Homophobic Organ Donation Ban

CONTINUED FROM PG. 1

PETITION LETTER:

Dear Commissioner Hamburg,

The ban on harvesting and transplanting certain tissues from homosexual donors is—like the ban on blood donations—absurd and homophobic. The scientific basis for such fear simply does not exist, and a government organization fostering homophobia is damaging to our society, which struggles daily to bring equality for all citizens indiscriminately. Refusing to allow certain tissue donations from homosexual donors is brutally denying their last wish over archaic phobias.

I urge you to harvest and transplant the healthy organs and tissue of HIV-negative donors without discrimination over their sexual orientation.

Sincerely,

[Your Name Here]

TSO Third Quarter Meetings Review

The July meeting of TSO was held at the Westchester Medical Center where we were joined by the New York Organ Donor Network's, Phoebe Kmeck, Volunteer Manager, and Sharan Bonder, Volunteer Associate from the New York Blood Center. The meeting was a training session focused on preparing volunteers to promote organ donation awareness in the community and at the NY Blood Center drives. Attendees learned about the organ donation registration process and received tips and suggestions regarding how the public could be addressed, how to answer questions, how to dispel myths around organ donation and how to tell your story as a way of encouraging organ donor registration. The NY Blood Center shared information about blood donation and the role of volunteers at their numerous drives. The partnership between NYODN and the Blood Center is continuing and offers great potential for us to reach the community, to provide education and awareness of donation, and of course, to register new organ donors. This meeting was very well attended and very appropriate for new and older volunteers.

The August TSO meeting was an open forum support meeting hosted by Mimi Greenman, WMC Transplant Social Worker, and Janet Ocasio, TSO Co-President and Social Worker. By picking up on the news of depression so prevalent in the media following very sad events, the meeting was able to use this as a starting point to have an open discussion about the issue of depression centered around health concerns, transplant, and disability. Caregiver concerns were discussed frankly and openly as we talked about sadness, disappointment, guilt, fear and loss. The group ended on a very positive note as attendees acknowledged that there is help and no stigma attached to seeking it out. Discovering that these feelings are common and expected offered relief to some who felt that they were alone in feeling this way. Attendees supported and reached out to one another in a very frank and honest discussion.

September's meeting brought us Robby Pixton, Hospital Services Specialist, New York Organ Donor Network. His talk centered around the organ recovery process and involved some of Robbie's actual experiences. He reviewed the moment of silence/prayer/reading that surgeons give to the donor before beginning any of the required surgery. This reverence given to the donor is very special and moving to everyone in the operating room. Detailed information about the order of recovery, what the surgeons look for, how the appropriate recipient is found, and how organs are transported were all part of this wonderful presentation.

Robby currently works as the donation process consultant for 32 of the 98 hospitals covered within NYODN's donation service area since February 2014. Prior to this position, Robby was traveling to all 98 hospitals, often in the middle of the night, as an organ preservation specialist. As a preservation specialist, Robby ensured each organ was safely recovered from consented donors, securely packaged and delivered to the accepting transplant center. Robby also leads the recovery of any solid organ deemed suitable for research. He has held this position since joining the organization in 2011.



Fund raising is a necessary part of any not-for-profit organization. Fund raising pays for our newsletters, our meetings, and our travel, among other activities. TSO has found several ways to make fund raising successful and fun at the same time.

One of the ways we accomplish fund raising is through becoming a member of TSO with your yearly dues. But another important way is through the Silent Auction activity at our Holiday Party.

Again, we are asking you for your help. Stop by your local pharmacy, liquor store, restaurant, or even a clothing store. The choices are limitless. Ask for a gift certificate of any amount. We will recognize your merchant at the holiday party and send the merchant a tax deduction letter for the gift.

We will send out more information via e-blasts in October and November. But thanks for all your help. We're looking forward to having another great Holiday Party and silent auction.

LIVING DONOR PROTECTION ACT - HR 5263

During the last U.S. legislative session, Representative Jerrold Nadler (D - NY) and Representative Michael Burgess (R-TX) introduced the Living Donor Protection Act to extend the rights of living donors. This is a very important piece of legislation, and a number of support and lobbying groups are working to move this bill along in the Congress.

We've reprinted a letter from TRIO that supports this bill. We've also included sample letters you can use to write to your US Representative and US Senator showing your support for this legislative activity.

H.R.5263 — 113th Congress 2013-2014

TRIO supports The Living Donor Protection Act.

The Living Donor Protection Act (HR 5263), sponsored by Representative Jerrold Nadler (D- NY) and Representative Michael Burgess (R-TX) was introduced on July 30, 2014 during the 113th Congress - 2013-2014.

At this time, while living donors are considered heroes and have saved and extended lives, insurance companies have all too often flatly denied insurance coverage to living donors (in some cases immediately denying applications after the surgery question is answered), limited coverage to living donors, raised premiums (which has drastically affected living donors) and declined life insurance, disability insurance, or long-term care insurance applications submitted by living donors.

This bill will protect living donors from insurance discrimination. The bill also has provisions for the promotion of education with respect to living donation.

H.R. 5263 makes it unlawful for insurance companies to discriminate against living donors by declining insurance, terminating insurance, limiting coverage and charging higher premiums for life insurance, disability insurance, or long-term care insurance policies just because someone identified as a living donor and stated that they gave the Gift Of Life as a living organ donor.

Additionally, the bill clarifies that living organ donors may use time granted through the Family and Medical Leave Act (FMLA) to recover from the transplant surgery.

On July 30, 2014 the bill was referred to committees within the House of Representatives including the Committee on Energy and Commerce, Committees on Oversight and Government Reform, House Administration, Education and the Workforce, and Financial Services.

While the bill is in committee discussions, TRIO once again calls on our friends and members to participate in our advocacy efforts by joining us in writing to our Members of Congress.

We urge you to email and send letters to members of Congress to gather support and additional co-sponsors for this bill. Also, you can publish more information on individual chapter website, including sample letters to express your support for this bill.

**Contacting your members of Congress can be done through two very easy-to-use websites. For members of the House of Representatives, go to the following website and type in your zip-code:<http://www.house.gov/representatives/find/>
For members of the Senate, go to the following website:
http://www.senate.gov/general/contact_information/senators_cfm.cfm**

Cosponsors:

**Rep. Burgess, Michael C. [R-TX-26]* 07/30/2014
Rep. Clay, Wm. Lacy [D-MO-1]* 07/30/2014
Rep. Costa, Jim [D-CA-16]* 07/30/2014
Rep. Fitzpatrick, Michael G. [R-PA-8] 08/01/2014**

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LIVING DONOR PROTECTION ACT - HR 5263

CONTINUED FROM PG. 5

Dear Senator _____,

Or

Dear Congressperson _____,

I'm writing you to express my support for H.R. 5263, the Living Donor Protection Act, introduced in the 113th Congress, 2013-2014.

The Living Donor Protection Act (HR 5263), sponsored by Representative Jerrold Nadler (D- NY) and Representative Michael Burgess (R-TX) was introduced on July 30, 2014 during the 113th Congress - 2013-2014.

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While the bill is in committee discussions, we urge you to support the efforts to pass this bill.

Sincerely yours,

Name

Address (address is very important to make sure your representative knows you are a constituent of the state or congressional district)

ALLIANCE FOR ORGAN DONOR INCENTIVES

There are many groups around the world working to strengthen society's perception and support of organ donation and transplantation. One of these groups is the Alliance for Organ Donor Incentives.

A case in point recently happened in Israel. Traditionally, Israel ranked very low on the list with people who register as organ donors. But through the efforts of ardent supporters on behalf of transplantation, such as Robby Berman and his Halachic Organ Donor Society and now his Alliance, registration efforts have increased markedly in Israel.

For more information, please go to the following website: <http://organdonorincentives.org/wordpress/>

Ravens player retires to give kidney to younger brother, a retired Steelers Player

By: **LAKEN LITMAN** September 17, 2014 4:48 pm ET

BALTIMORE — Ma'ake Kemoeatu missed his final collegiate football game because the NCAA suspended him for improperly providing textbooks to his younger brother.

He was a four-year starter at Utah on scholarship and his little brother Tevita was a walk-on. Their parents didn't have enough money to buy books, so Ma'ake bought them for him and therefore couldn't play in the Las Vegas Bowl against USC.

But Ma'ake wasn't trying to cause trouble. The oldest of seven kids, he steps up for his family when they need help.

So when his brother Chris needed a kidney transplant this past August, Ma'ake, a former nose tackle for the Baltimore Ravens, didn't hesitate when he heard the news. He was going to donate.

When Chris was in eighth grade, he started having kidney pain. Over the years, as he grew into a 6-foot-3, 385-pound lineman for Utah and go on to win two Super Bowls with the Pittsburgh Steelers, the pain got worse.

He played through it. Training camp, regular season practice, games and playoffs. With what was later discovered to be a form of kidney disease. He grew up in a tough family. A family that rarely said 'I love you' not because they didn't have feelings, that's just how it was.

"I've seen him struggle and the last three years of his career, fighting through a lot because of his kidney," Ma'ake said at a press conference at the University of Maryland Medical Center on Wednesday. "When we found out he needed a transplant, we had to stop our careers because his health was most important to us."

After the 2011 season, the pain was too much and Chris stopped playing football. Ma'ake ended his career with the Ravens after the 2012 season to be with his brother.

About a year into the process after the weight had been lost, doctors discovered Chris had heart problems and needed surgery. He underwent heart surgery this past June and six weeks later on Aug. 27, they did the kidney transplant.

It was successful and the brothers are doing well. Dr. Stephen Bartlett, who performed the transplant, said Ma'ake's kidney was the largest he had ever seen.

"It was one-and-a-half times bigger than any other kidney I had ever seen in my life," Bartlett said. "It was absolutely remarkable."

Recovery takes six weeks and the brothers are about halfway finished. The doctors said they're both "functioning beautifully." They're living down the street from the hospital for now, but plan to move home to Hawaii once they've been cleared.

A return to the NFL is unlikely. Ma'ake has reached out to Cleveland Browns linebacker Paul Kruger, who plays in the league with one kidney, but the brothers want to spend time with family and friends in Hawaii. Chris spent eight years in the NFL and Ma'ake played for 10, and they have businesses and foundations to tend to.

As if the family wasn't close enough — while the brothers were preparing for surgery, they said different siblings would come from Hawaii to stay with them and cook and clean the house — they say 'I love you' more these days.

"We were raised in a tough atmosphere," Ma'ake said. "But after this, I think we say it."

Then he turned to his brother Chris and said, "I love you man."

FINANCIAL SUPPORT FOR IMMUNOSUPPRESSIVE DRUGS

Many of the pharmaceutical companies now have programs to assist people to purchase these drugs. Please check out any of the following websites for more information:

<http://www.transplantliving.org/before-the-transplant/financing-a-transplant/directory/>

<http://www.americantransplantfoundation.org/about-transplant/resources-and-links/5408-2/>

<http://bethematch.org/For-Patients-and-Families/Getting-a-transplant/Planning-for-transplant-costs/Financial-assistance-for-transplant-patients/>

<http://www.transplants.org/>

<http://bonemarrow.org/financial-assistance/>

Transplant Milestones

Many of you may not know the history of transplantation in the 20th century. This article summarizes a number of important events.

Researchers began experimenting with organ transplantation on animals and humans in the 18th century. Over the years, scientists have experienced many failures, but by the mid-20th century, they were performing successful organ transplants. Transplants of kidney, liver, heart, pancreas, intestine, lungs, and heart-lungs are now considered routine medical treatment.

In the last 20 years, important medical breakthroughs such as tissue typing and immunosuppressant drugs have allowed for a larger number of organ transplants and a longer survival rate for transplant recipients. The most notable development in this area was Jean Borel's discovery of a drug for immunosuppression called Cyclosporine in the mid-1970s. This drug was approved for commercial use in November 1983.

The need for organ transplants continues to exceed the supply of organs. But as medical technology improves and more donors become available, the number of people who live longer and healthier lives continues to increase each year.

Transplant Milestones in the United States and Canada

1954	First successful kidney transplant* Dr. Joseph E. Murray, Brigham & Women's Hospital, Boston, MA
1966	First successful pancreas/kidney transplant Drs. Richard Lillehei, William Kelly, University of Minnesota, Minneapolis, MN
1967	First successful liver transplant* Dr. Thomas Starzl, University of Colorado Health Sciences Center, Denver, CO
1968	First isolated pancreas transplant Dr. Richard Lillehei, University of Minnesota, Minneapolis, MN
1968	First successful heart transplant Dr. Norman Shumway, Stanford University Hospital, Stanford, CA
1981	First successful heart-lung transplant Dr. Bruce Reitz, Stanford University Hospital, Stanford, CA
1983	First successful single lung transplant* Dr. Joel Cooper, Toronto Lung Transplant Group, Toronto General Hospital, Toronto Canada
1986	First successful double lung transplant* Dr. Joel Cooper, Toronto Lung Transplant Group, Toronto General Hospital, Toronto Canada
1989	First successful living-related liver transplant Dr. Christoph Broelsch, University of Chicago Medical Center, Chicago, IL
1990	First successful living-related lung transplant Dr. Vaughn A. Starnes, Stanford University Medical Center, Stanford, CA
*Transplant was the first of its kind in the world	

Happy Re-birthday to You!



Our best wishes to all our TSO friends and participants who are celebrating re-birthdays in October, November and December. Our sincerest wishes for many more happy and healthy years to come!

Save the Date...



TSO Holiday Party

Make way for the season of parties and celebrations! At the top of our list is the ***TSO Holiday Party on Monday, December 8, 2014***

Our celebration will take place at the Doubletree Hilton in Tarrytown, NY starting at 6 p.m. We have kept the ticket price at the same level as last year, so we hope you will all plan to be there and join us. We will send out additional information within a few weeks through email and mail.

TSO Wants You!

We encourage you to participate in our meetings and activities. Recipients, caretakers, living donors, donor families, and interested individuals are all members of our organization. In addition to our meetings, there are numerous volunteer activities we can offer to you.

For further information, please check out our website:

www.transplantsupport.org.

You can also find us on Twitter and Facebook. Check out:

<https://www.facebook.com/pages/Transplant-Support-Organization/158539687509?fref=ts>

https://twitter.com/TSO_Support

And you can always contact us via email at: email4tso@gmail.com

CALL FOR VOLUNTEERS - TSO NEEDS YOU!!



TSO is proud to participate in donor awareness drives in the community.

Promoting organ donor awareness is a key part of our mission.

Volunteers are the link to the community.

By attending a community event, offering information about transplant and organ

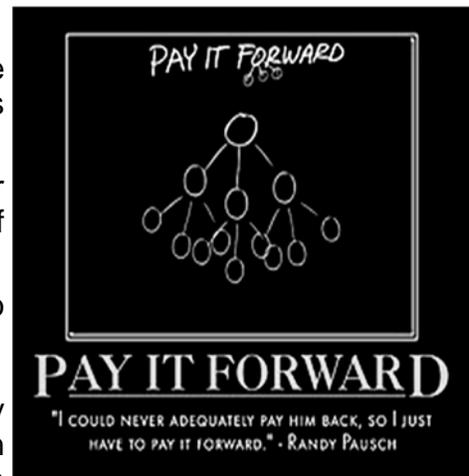
donation, registering new organ donors is one of the most important functions of our organization.

Pay it forward! Say thank you for your gift of life by volunteering. At the same time, make new friends and enjoy attending a variety of events.

NOT SURE YOU ARE QUALIFIED? NO SPECIAL SKILLS ARE NEEDED, JUST A WILLINGNESS TO HELP. TRAINING SESSIONS ARE AVAILABLE WHICH ARE GIVEN BY TSO AND THE NYODN.

FOR MORE INFORMATION PLEASE CONTACT

JANET OCASIO AT www.email4tso@gmail.com.





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: October 15, 2014

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.*