

T S O

TRANSPLANT SUPPORT ORGANIZATION



Serving Westchester, Putnam, Dutchess, Bronx Counties and Southern Connecticut
VOL. 18, ISSUE 2 MARCH/APRIL 2013

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Meeting Dates

3/20/2013
4/17/2013
5/15/2013
6/19/2013

And the Beat Goes On

Our speaker for the February meeting was Elizabeth A. McNamarra, RN, MSN, from Musculoskeletal Transplant Foundation {MTF}, a truly knowledgeable and inspiring presenter. The MTF is the largest Tissue Processor in the United States. Elizabeth works with Donor Families and Recipients. She is dedicated and devoted to helping both, as she experiences the thrill of Life renewed with every successful "gift" of tissue donation. She explained that the hardest thing to do is "ask" the family to help others through tissue donation; but it is also the most rewarding act. In death, these families are "paying it forward". In turn, it also makes it possible for recipients to go out, tell their stories and educate the world about donation.

The majority of the world does not know anything about tissue donation, because it does not make the 11 o'clock news. In fact, we can donate corneas, skin, bone, heart valves, tendons, ligaments, veins. Elizabeth explained that one does not have to die of brain death to be a tissue donor. Tissues are removed after the heart stops beating. One donor can improve the lives of over 50 people through tissue donation. The MTF uses a cut-off of age 65 for tissue donors. As is the case for organ donors, there is also a need for more tissue donors. As we all age, our bones, especially, are not suitable for transplant.

Everyone present thoroughly enjoyed the informative presentation.

Transplant Support Organization meetings are held at 7 p.m. on the third Wednesday of the month (with some exceptions) at Westchester Medical Center, Taylor Building, Valhalla, NY.

**Schedule for monthly meetings
hosted by Westchester Medical Center**

7:00 PM — Social Time 7:30 PM-9:00 — Meeting and program for evening

March 20th - Diane Poonai, Social Caseworker with Westchester County Senior Programs and Services. Topic: "Medicare regulations, Medicare plan options, and Benefit programs"

March 19th - Training Session, 5 to 8 p.m. at Westchester Medical Center's Taylor Pavilion Media room on the 1st floor. Dinner will be provided. RSVP to Janet Ocasio — GKJP@aol.com

Future Meeting Agendas

April 17th - Tribute Meeting

May 15th - Jennifer Goldwasser, MD (Dermatologist). Topic: "Taking Care of Our Skin"

June 19th - Harry Kiernan, Executive Director National Living Organ Donors Foundation, Inc. Topic: "How We Can Increase Organ Donations Through Living Donation"

July and August - Combined WMC/TSO Meetings

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, 1154 Webster Avenue, New Rochelle, NY 10804

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

You do not have to be a facebook member the access this account.

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 - GKJP@aol.com

The UNOS National Patient Waiting List

Candidates as of 2/15/2013

95,335 patients waiting for a kidney transplant.
15,784 patients waiting for a liver transplant.
1,197 patients waiting for a pancreas transplant.
2,124 patients waiting for a kidney-pancreas transplant.
255 patients waiting for an intestine transplant.
3,431 patients waiting for a heart transplant.
53 patients waiting for a heart-lung transplant.
1,660 patients waiting for a lung transplant.
117,254 TOTAL PATIENTS

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

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TSO Annual Elections

According to the bylaws of TSO, every April our officers are elected to serve one year terms, and one third of our board is elected as well to serve a 3 year term.

For our organization to continue to prosper, fresh ideas and strategies need to be given an opportunity to grow. Therefore, if you would like to be considered for a position as an officer or board member, contact Janet Ocasio at 845-582-0430 or gkjp@aol.com.

Happy Rebirthday to You

Priscilla Kilgour	Kidney	March, 1992	George Belezaire	Kidney	April, 2005
Anne Landisi	Kidney	April, 1994	Michael Murphy	Kidney	March, 2006
Wayne Grossman	Kidney	March, 1996	Sara Marshall	Kidney	April, 2006
Yvette Sharrow	Liver	March, 1997	Helen Harper	Kidney	March, 2007
Janice Maron	Kidney	April, 1997	William Becker	Kidney	March, 2008
Hermenegildo Correia	Kidney	April, 2000	David Holt	Heart	April, 2008
Nader Elnimri	Kidney	April, 2001			
Barbara Mattioli	Kidney	March, 2002			
Joseph Ramos	Kidney	March, 2002			
Gerhard Freyer	Kidney	April, 2002			
Angela Chebetar	Liver	April, 2002			
David Juliano	Kidney	March, 2003			
Efrain Roman	Kidney	April, 2004			
Marilyn Heideman	Liver	April, 2004			
Bobby Iaboni	Kidney/Liver	March, 2005			



Our best wishes to all for many more happy and healthy years to come!

Quinoa Convenience

After 10 years of working in farmers' markets, Chef Nathan Lyon knows the joys of fresh food. He also knows that if a food is versatile, people will never tire of it. Which is one reason Lyon gets excited about quinoa. "It's so adaptable," he says. "You can eat it for breakfast, lunch or dinner, depending on the preparation — and it takes on different flavors really well."

Lyon, who is the author of *Great Food Starts Fresh* (Self-published, 2011), host of the television show *Good Food America* (Veria Living) and co-host of *Growing a Greener World* (PBS), talked with Experience Life about the joys of quinoa and his favorite ways to prepare it.

Why is quinoa becoming so popular?

I think people get excited about quinoa when they realize how easy it is to prepare. Convenience is one of the things this country embraces. Plus, quinoa has a firm texture with a slight crunch and a very nice earthy, nutty flavor. On top of all that is the nutrition. Quinoa is gluten-free and it's a complete protein, a major bonus for those who don't eat a lot of animal foods.

What's a typical rookie mistake with quinoa?

It's pretty user-friendly, but people have a tendency to overcook it. When you overcook quinoa, it loses the wonderful crunchiness that is part of its appeal.

What are some great, simple ways to eat quinoa?

Salads. You can make a warm, yummy kale-quinoa salad by cooking quinoa and mixing it with toasted walnuts, potatoes and kale cooked with curry powder, onions and garlic. I also like quinoa, corn and black bean salad dressed with lemon, cumin and olive oil. Or quinoa with grilled vegetables with that same dressing.

Any favorite recipes?

My Spicy Lemon Quinoa Salad in *Great Food Starts Fresh* is super simple. Open a can of garbanzo beans while the quinoa is cooking. Rinse and drain the beans. Chop up some kalamata olives. Get out your feta cheese and toast some pine nuts. Make a quick lemon citronette with fresh lemon juice, chopped shallot and extra-virgin olive oil. When the quinoa is cooked, mix all the components together and add some crushed red pepper flakes. It's fast and easy to make, and ridiculously refreshing and satiating.

What are some other savvy ways to prepare quinoa?

You can cook it in stock or broth instead of water to add richer flavor. You can also prepare quinoa like a rice pilaf with onions, garlic and olive oil — or do it risotto style. You can use it in sushi or as a base for chili. You can also make a really good quinoa tabouli, a Middle Eastern salad that traditionally uses bulgur wheat. For breakfast, you can make it into a cereal and mix it with dates, a little bit of yogurt and toasted almonds. Instead of steel-cut oats, which take 45 minutes, sub in quinoa, which cooks in just 15 minutes. It packs a lot of protein, has a lower glycemic index, and when compared with oatmeal, I think both the taste and texture are better.

Quinoa Nutritional Know How

- Quinoa is gluten-free
- With an almost perfect balance of all nine essential amino acids, quinoa is considered a complete protein.
- It is lower in carbs than brown rice, and higher in fiber, protein, calcium, and iron.
- Quinoa is high in phytonutrients, powerful plant-based micronutrients that offer many health benefits and help ward off chronic disease. Specifically, quinoa is rich in flavonoids, with antioxidant properties that ward off inflammation.
- This seed contains healthy fats like alpha -linoleic acid [an omega-3 fatty acid].
- There is a low risk of allergy with quinoa and a high degree of digestibility, making it a great food for young and old.

Clark Beck was told new kidney might only last months...

By Debbie Juniewicz

Clark Beck, 83, will celebrate the 40th anniversary of his kidney transplant on Oct. 29.

According to the United Network for Organ Sharing,

Beck is considered to be among the longest living survivors in the world with a functioning kidney

Clark Beck didn't set out to be a pioneer, just a student.

But after Purdue University told the young black man that "your people cannot be engineers" he continued on. With transcript in hand, he tried the University of Cincinnati the very next day

"The dean looked at my transcript and told me, 'You're going to catch hell from both sides of the desk,'" Beck said. "There was only one other black student in the engineering school at the time."

The Harrison Twp. man was ready for the challenge and enrolled in the university's College of Engineering and Applied Science in 1951. He earned a bachelor's degree in engineering and later a master's degree in aerospace engineering.

His challenges weren't limited to getting an education as he started to develop serious health problems in the early 1970s.

"I had a rough time when I was in school, I didn't have enough money to eat well or take care of myself," he said. "I got sick and the strep throat settled in my kidneys. I didn't know at the time the damage it did."

Beck, who was working as an engineer at Wright-Patterson Air Force Base and teaching at Central State University, continued dialysis and waited for a kidney to become available. He almost missed his chance, however, on a late fall afternoon almost a year after he discovered he needed a transplant.

Beck went out early on a Saturday morning with his surveying class and missed the phone call alerting him that a kidney had been recovered from a deceased donor that morning. He didn't get the message until Saturday night.

"The doctor told me that the kidney had a 50 percent chance of lasting six months," he said.

Beck's doctor might have underestimated a bit. The 83-year-old will celebrate the 40th anniversary of his transplant on Oct. 29. It is a significant milestone as Beck is considered to be among the longest living survivors in the world with a functioning kidney, according to the United Network for Organ Sharing.

But with Beck, it's about more than quantity, its quality of life that matters.

"Any chance he has to make a difference, he takes it," said Cathi Arends of Life Connection Ohio. "Whether it's mentoring a young person or giving someone who needs a transplant hope, he is there for them. One of the things he frequently says is that he wanted to make the most of his second chance and he has done just that."

Beck founded the Wright STEPP program at Wright State University in 1987. The Science, Technology, and Engineering Preparatory Program was designed to enhance the development and education of youth underrepresented in the fields of engineering, math, and science.

Beyond the classroom, Beck had a 31-year career at Wright-Patterson and was the first black president of the Dayton Engineers Club. He is a Donate Life Ambassador for Life Connection of Ohio and serves on several community boards.

"He is our voice in the community and we are so glad to have him working with us," Arends said.

And Beck is happy to have the opportunity, just like he was when he was given the opportunity by the University of Cincinnati more than six decades ago.

"I was definitely a pioneer in many ways and I'm proud of that," he said.

LETTER FROM THE PRESIDENTS

Dear friends of TSO,

We hope that this winter has not been too harsh for you and your family. TSO was forced to cancel the January monthly meeting because of inclement weather. The scheduled speaker has agreed to be rescheduled to a later date and we will be working on this. We are considering not planning January meetings in the future since this is not the first time that a January meeting has been canceled due to the weather. We welcome your feedback. In addition, I would like to encourage you to provide us with an email address so that when we need to make a sudden change we can communicate with you. If you are not sure if your email address with us is current, please send me your email. If you do not have an email address, let me know and I will start a call list.

In this newsletter you will see two announcements, one for the Celebration of Life event at St. Patrick's Cathedral on April 6th at 2PM and the second to let you know that April is Donate Life Month. There will be events throughout the area sponsored by numerous agencies related to this event and we encourage you to attend with your loved ones. We will post notices on our Facebook page: transplant support organization. Please visit our page for notices and interesting current news stories about organ donation and transplantation.

In April TSO will hold our annual elections for officers and board members. If you are interested in any position please inform us of your interest. A notice will go out to inform you of the results of this election.

TSO is busy planning the direction for the upcoming year. In response to your requests we will be looking at ways of increasing our support services beginning with the 2 summer support TSO meetings together with WMC's Social Worker, Mimi Greenman. We are looking for your ideas and interests. TSO is strongly dedicated to the mission of support for our transplant community. We will continue to provide the education because we strongly believe that education is the key for your continued health and empowers you to play a vital role in sustaining your health and well being. This being said, emotional and social support cannot be underestimated and we will address this with you. We want to know if TSO members are having a difficult time, if you are hospitalized, if you need friendship and support. You can post your status on Facebook or call one of the board members. Facebook is monitored multiple times a day, so if you write a message we will respond.

So for now, thank you for all of your help in fulfilling the mission of our organization.

Wishing you the best,
Janet Ocasio and Jeff Graham-Co-Presidents

Save the Dates

On Tuesday, March 19th from 5 to 8 p.m.

TSO will be joined by the NYODN and the New York Blood Center to offer you a unique training experience

TSO IS JOINING THE NYODN AND THE NEW YORK BLOOD CENTER TO EXPAND OUR REACH IN THE COMMUNITY BY WORKING TOGETHER.

THIS TRAINING SESSION WILL ALLOW YOU TO BECOME DUALY TRAINED BY TSO/NYODN AND THE BLOOD CENTER.

THIS IS THE FIRST TIME THAT WE HAVE BEEN ABLE TO OFFER YOU THIS OPPORTUNITY.

If you are a volunteer for organ donation, if you want to be a volunteer, or you just want to learn more about the organ donation and community outreach, please plan to attend.

The training session will be held in the Westchester Medical Center's Taylor Pavilion, Media Room on the 1st floor.

Dinner will be provided

So mark you calendars for this important opportunity to learn amongst friends and enjoy a warm and educational experience together.

All are welcome

RSVP to Janet Ocasio via email at gkjp@aol.com



We've already started our planning for another great holiday get-together for 2013

So, please mark your calendars!

Monday, December 9, 2013

at the Doubletree Hotel in Tarrytown, New York

We hope to see you there!

Implantable Artificial Kidney Could Help Tens of Thousands: An Interview with Shuvo Roy, PhD

By: Delicia Honen Yard

With nearly 100,000 patients awaiting a kidney transplant and fewer than one-fifth likely to undergo the procedure each year, a promising hybrid device that works from the inside to provide renal functions beyond dialysis 24 hours a day, seven days a week, has the potential to change a lot of lives, not to mention substantially lower Medicare costs.

Shuvo Roy, PhD, associate professor in the Department of Bioengineering and Therapeutic Sciences at the University of California San Francisco School of Pharmacy and technical director of The Kidney Project (<http://pharmacy.ucsf.edu/kidney-project/>; [Facebook.com/ArtificialKidney](https://www.facebook.com/ArtificialKidney)) updates Renal & Urology News on his group's work.

How did you begin to develop the artificial kidney?

Dr. Roy: In the early 2000's, we proved that the science worked. We took off-the-shelf, bulky, large, technology that we hooked up in a circuit to mimic how our kidneys work, and my colleague at the University of Michigan, Dr. David Humes, applied this to about 60 intensive care unit (ICU) patients who were suffering from acute renal failure. About half of them survived beyond six months longer than they would have lasted on dialysis.

That clinical trial gave us a lot of confidence that this concept of a filter plus a bioreactor actually does provide a therapeutic benefit. But then the question became, "How do we take this concept from the large-scale technologies of the ICU and apply it to people who go to the dialysis center three times a week?"

And what was the answer?

Dr. Roy: The medical director on our team, William Fissell, MD, who is a nephrologist [with an engineering degree from Massachusetts Institute of Technology Eds.], said we'd have to shrink the technology into something smaller that could be implanted; that could allow patients the freedom of mobility and the ability to eat and drink normally; and that could operate continuously, 24/7, to provide the benefit of toxin removal as well as the biological functions of the kidney that dialysis does not provide, such as help regulate blood pressure, help produce vitamins, and help with the acid levels of the blood.

How does the function of the artificial kidney differ from dialysis?

Dr. Roy: The five-year survival rate for dialysis hovers around 35%, but for kidney transplantation, it is well beyond 80%. The reason for that is dialysis simply does not provide the biological functions of a healthy kidney.

Our device mimics the native kidney, with a filter serving as the glomerulus. The filter is followed by a tubule the bioreactor which is lined with cells, to provide the full functions of a kidney. In typical dialysis you just do the filtration part; you don't mimic the cell part at all.

Our device will be connected to the blood vessels, as a kidney transplant would be. One very exciting aspect is the membrane technology we have developed for the hemofilter: It's so efficient that it will allow for filtration without the need for an electrical power supply, connections to the outside, or a battery. So just based on the blood pressure, we will be able to get therapy that's sufficient to keep the patient alive 24/7.

What is the status of the artificial kidney now?

Dr. Roy: Over the last 10 years, we have been on a journey to miniaturize the components of our device to the size of a small to-go coffee cup using silicon nanotechnology. We enclosed the cells of the bioreactor in a container with tiny windows that allow for interaction between the body and cells but prevent the body's immune system from getting to these cells.

We showed this to work on the bench, in small animals, in sheep, and in pigs with much success; it is all working in principle. The next step, which is what we are starting now, is to integrate the filter and the bioreactor into a single compact unit and do the animal testing that will let us validate this for subsequent human study.

I think we will be ready to test in humans by 2017, if not before. We are collaborating closely with the FDA as part of the agency's Innovation Pathways 2.0 program to design this research.

How temporary or permanent would the implanted artificial kidney be?

Dr. Roy: It's hard to say prospectively without doing the studies, but we hope that it will be one surgery to implant it, and that should be it. But we also recognize that you have to plan for maintenance or replacement: The filter could get clogged up, or the cells could die.

So, we have thought of a strategy where the artificial kidney gets implanted right underneath the skin. That way, components can be replaced in a minimally invasive procedure, which would probably be performed by a vascular surgeon. We do not anticipate the whole device having to be removed.

Based on our lab studies and what we can project, we think that no maintenance will be needed for at least one year.

From the February 2013 Issue of Renal And Urology News

DIRECTIONS TO WESTCHESTER MEDICAL CENTER TAYLOR BUILDING

*****See note at bottom of page for Taylor Building*****

Taconic Parkway SOUTH

to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Route 684 SOUTH

to Saw Mill River Parkway to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Saw Mill River Parkway SOUTH

to Sprain Brook Parkway to Medical Center exit (just past New York State Police Headquarters). Make right at top of exit onto Route 100 (south). Follow to entrance to Medical Center grounds on right.

Saw Mill River Parkway NORTH

to 1-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-87 (New York State Thruway) SOUTH

to Tappan Zee Bridge. I-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-87 (New York State Thruway) NORTH

to 1-287 east to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

Sprain Brook Parkway NORTH

to Medical Center exit. Make left onto Medical Center grounds.

I-95 (New England Thruway) NORTH or SOUTH

to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Hutchinson River Parkway NORTH

to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Meritt Parkway SOUTH

to Hutchinson River Parkway to 1-287 west (Cross Westchester Expressway). To Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

Bronx River Parkway NORTH or SOUTH

to Virginia Road exit. West on Virginia Road to Route 100 (Grasslands Road). Make right, and follow to stop light at junction of routes 100 and 100C. Make right onto Route 100 north. 1 mile to entrance to Medical Center grounds on left.

I-287 (Cross Westchester Expressway) EAST

to Exit 4 (Route 100A north, which becomes Route 100 north). 3.2 miles from exit to entrance to Medical Center grounds on left.

I-287 (Cross Westchester Expressway) WEST

to Sprain Brook Parkway north. To Medical Center exit. Make left onto Medical Center grounds.

*****Taylor Building*****. After entering Medical Center Grounds (left at Wood Road), turn right onto Westview Drive. Wind around about 1/10 mile until you see sign for Taylor building on right. Park in front and go to A/V room.



TSO Transplant Support Organization

Participant Application: New Renewal

Please fill out this form and mail it with your tax-deductible contribution to:
TSO, 1154 Webster Ave., New Rochelle, NY 10804

NAME(s) _____

Mailing Address: _____

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

Email: _____

PERSONAL INFORMATION (optional)

Birthdate: _____ Sex: _____ Marital Status: _____

Occupation: _____

CANDIDATE / RECIPIENT INFORMATION — Please check appropriate description

Transplant Recipient _____ Transplant Candidate _____ Family Member _____

Donor Family Member _____ Interested Individual _____ Professional _____

Have you already had a transplant? Yes _____ No _____

Type of Transplant(s) _____

Date of Transplant _____ Time waited (or waiting) _____

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 members, same address) \$35.00

Additional participants at same address \$10.00 each

Professional (Surgeon, Physician, Clinical Coordinator, Nurse, Social Worker, etc.) \$25.00

Additional optional voluntary contribution (at your discretion) \$ _____

I would like to take an active role within TSO (please check all areas of interest):

Speaker _____ Membership Drive _____ Fund Raiser _____

Clerical _____ Contributor _____ Patient & Family Support _____

Newsletter _____ Date Processing _____ Other _____

Help Promote Donor Awareness License Plate Frames For Sale

\$ 10.00 each 2 for \$ 18.00 3 for \$ 25.00



LPF 1 Top: Make a Miracle
Bottom: Be an Organ Donor

LPF 7 Top: Transplantation Works
Bottom: Lung Recipient

LPF 2 Top: Miracle Maker
Bottom: Kidney Donor

LPF 8 Top: Transplantation Works
Bottom: Liver Recipient

LPF 4 Top: Organ / Tissue
Bottom: Donor Family

LPF 9 Top: Transplantation Works
Bottom: Heart Recipient

LPF 10 Top: Transplantation Works
Bottom: Kidney Recipient

Name _____
Address _____
City, State, Zip _____
Phone _____
Frame(s) desired _____

(add \$2.00 for postage and handling)

Send order with payment to: TSO, 1154 Webster Ave. New Rochelle, NY 10804

Save the Date

“Remember and Rejoice”

**TRIO Manhattan Chapter cordially invites you to attend
our Annual Ecumenical Service**

*Come join us as we “Remember” our donors and their families who so generously
have given the “Gift of Life” and “Rejoice” with recipients who have received this
special “gift”.*

Saturday, April 6th, 2013 at 2:00 PM

St. Patrick’s Cathedral

Fifth Avenue, between 50th & 51st Streets, New York, NY

For more info call Ira Copperman or Glenda Daggert: (212) 222 - 8386
or email them at: irajay2004@gmail.com or gdaggert@gmail.com

TSO
Transplant Support Organization
1154 Webster Ave.
New Rochelle, NY 10804

NEXT MEETING: March 20, 2013

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.*