



A newsletter of the Transplant Awareness Organization of Greater Rochester
 Providing support, understanding, education & resources for transplant recipients, candidates & their families

Transplant Times

October - November, 2013

www.tao-rochester.org

1.888.664.1463

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A Message from the President

I hope that everyone had a great time with family and friends this summer. We had a good turnout for the TAO picnic and I would like to thank Debbie, Bonnie and all who helped to put the picnic together. Check out the pictures of the picnic on the web site. You may see yourself in one of them.



This is the start of a new year for TAO and we are hoping to see our membership increase. Whether you are a candidate or a transplant recipient, living donor or a care giver, all are welcome at our monthly meetings and special events. This is a chance to hear other transplant peoples stories and ask questions. Your situation may be similar to someone elses, and you or they might be able to help someone else, or you could pick up an idea that might help you. As a lung recipient, I enjoy talking to other people and listening to their stories, we can all learn from one another. Meetings are on the third Monday of the month at 6:30 (*New Time*) at the Christ Episcopal Church in the Fellowship Room, 36 South Main Street, Pittsford, New York. Come and join us.

Gentech will be our guest speaker. He will talk about the immunosuppressants Cellcept and Valcyte and how they are used to prevent organ rejection in transplant recipients.

ROC the Day is on December 11. Please mention to your coworkers and friends that they can make a one-time donation to TAO via the United Way by using our number (2493). Last year we received \$172 from three individuals, and all of TAO is thankful to them. We are also thankful for our faithful contributors that designate TAO as the recipient of their annual United Way contribution.

The days are getting shorter and we should all prepare for winter. Remember to get your flu and pneumonia shots this fall in preparation for the cold and flu season. Staying healthy is a full time job!

I would like to thank all the board members for their hard work and help. Without them we would not have accomplished as much as we have this year.

Matt Felo

**Membership Meeting
 Guest Speakers / Topic**

October 21 @ 6:30 p.m.
**Doug Doehring -
 Genentech**
**"Immunosuppressants -
 Cellcept and Valcyte"**

November 17 @ 6:30 p.m.
**Check the TAO website or
 Facebook page for up to
 the minute details**

TAO Meets

**3rd Monday of the Month
 6:30 P.M. (NEW TIME)**
**Christ Episcopal Church
 Fellowship Room
 36 South Main Street
 Pittsford, NY**

New Start Time for Meetings is now 6:30 PM

TAO HAPPENINGS . . .

Kidney Walk Seneca Park Zoo

A beautiful sunny Sunday at the Zoo brought out walkers for the Kidney Cares Walk. It was the second annual walk and recipients, their families and staff participated. TAO was on hand to pass out water bottles to the participants. Monies raised will be used to continue their good work in the community.

PGA Week

Thousands of visitors were in Rochester for the PGA Tournament at Oak Hill during the week of August 5. Among them was pro golfer Erik Compton.

Erik is best known throughout the golf world for his two heart transplants. His first heart transplant came in 1992, when he was 12 and his second transplant in 2008. For this, Compton was honored with the Ben Hogan Award in Augusta, Georgia during the Masters in April 2009. Erik has also received the 2912 Babe Didrikson Zaharias Courage Award from the U.S. Sports Academy. In 2013, Erik was among many distinguished recipients of the Donate Life Champion award. This award is given to role models in the sports community who have made a difference by inspiring others through their support for organ donation.

Although not competing at Oak Hill, he was the featured guest at the Genesee Valley Club Thursday, August 8 where he shared his inspiring story of perseverance and courage and provided his insights about the PGA Tour. TAO Board member Norm Breen had the opportunity to meet with Erik and share his heart transplant experience with him.



Eric Compton (L) with TAO Board member Norm Breen

ATBGO . . .

The Seventh Annual **And the Beat Goes On. . .** fundraiser was held on Saturday, June 15 at the Double Tree hotel. Good food, good times and spirited auction bidding proved to be successful in raising money to help keep our house open! Thanks to all who were able to attend and support the Harbor House of Rochester.

TAO Sponsors Hole Sign @ Brighter Tomorrow Golf Tournament

TAO was a proud hole sponsor at the Rochester Eye & Tissue Bank's inaugural golf tournament – Brighter Tomorrow – on Monday, September 16 at Shadow Lake Golf Club. All 54 golfers enjoyed the day, regardless of the cool, rainy weather.

Funds raised will help support programs, such as public and professional education, that are vital to increasing the number of eyes/corneas, organs and tissues that are needed for transplant.

TAO Pizza Party - Social Event

In keeping with suggestions from our recent poll, TAO conducted a pizza and wings party September 16 at Christ Church in Pittsford. We had a great turnout and did justice to the pizza and wings, salad and cookies.

Geoff Foley welcomed everyone and played host to the group as we went around the table sharing stories of our transplant experiences.



My Story

By: Maria Hasenauer

In December of 2007, I came down with a fever of 100 degrees. Like any other normal human being, I thought it was the flu, so of course I went to the store and bought over the counter medicine. By Christmas time I was getting worse. I could not go very far without losing my breath and I started getting back pain around my kidneys. I went to the family doctor and was put on a pain medication and an antibiotic to help with what we thought to be a kidney infection.

December 27, 2007, my husband, John, and my daughter, Ria, took off early that morning to head to South Carolina. John called four hours into the trip to see if I wanted them to come home. I said, "No, I will be fine. Ria really wants to see her cousins." Later that night, I went to take a bath and when I was finished I would barely walk to the couch. I felt like I was going to faint. My girlfriend, Chris, called to talk and I asked her to come over. When she got to the house we took my temperature and it was 101.5 degrees. I called my doctor and he told me to go to hospital. So we went to Rochester General Hospital, as that was the closest.

When we had got to the emergency room they put me in a hall bed which was very small. They took all kinds of blood tests. This was about 7 pm. At 1:30 am they finally came to me with information, it was information I did not want to hear. They said, "You are highly anemic, which is usually caused by leukemia." This was like a slap in the face. I started making phone calls at 2 am to my family in South Carolina, even though they had just arrived five hours prior. My sister, Debbie and other daughter Ashley came to wait with me for the news.

December 28 the doctor came in and told me that all of the tests were positive for leukemia. So Debbie got me out of bed and gave me a shower because I was so weak. Around noon all of my family and friends started to come to the hospital to see me, they were coming all day long. When the doctor walked in he said, "We need to get you a bigger room. You have too many friends and family." All we could do was laugh. John and Ria arrived at about 2 am after they had already moved my floor and room. All I could think about was them not being able to find me but they did. The nurse, that was on staff that night, brought in ice cream for everyone to share. It was so sweet.

December 30, all of my family was at the hospital with me and I was moved to a much larger room. Debbie decorated my room, from the walls, to the windows and even the bathroom. It was pretty cool seeing as I would be there for one month. A lot happened on this day. I got a lot of information about how the chemo was going to work from the doctor. The surgeon explained how he was going to put in my Hickman Catheter. Later that same day, Kelly, my best friend, showed up and spent that day and

all through the night with me in the hospital. The next day was the 31st, New Year's Eve; Kelly took me to the family waiting room to watch the fireworks. And it was another great visiting day with all of my friends and family.

January 2, 2008, I woke up with such a pain in my back. John was in my bed holding me. I didn't even know that he was there. I asked for a pain pill and was told that I was going down for surgery in a little bit. So there was no chance of me getting anything to eat or drink that morning. I had to wait till after the surgery. I was brought to pre-op to prepare for the surgery to put in the Hickman catheter. One of the nurses that were there went to take my blood pressure, so for some reason she chose the arm with my IV and blew out my vein. The anesthesiologist came in to because I needed to get platelets. He worked for ten minutes to get it in. I was finally off to surgery. Before I went to the surgery, they said that it would only take about an hour, but this took two and a half hours. I was bleeding onto the table and they were pumping in blood and platelets. I came out of surgery in a good mood, even though I did not know what was going on in surgery. Two days later I had gotten a hematoma in my neck from the Hickman in my jugular vein. They said I was going to have it for about month but it was gone in days. That was a very long month.

January 28, 2008 was the day that I was able to go home. It was the best feeling I ever had, knowing that I was able to go home and just lay in my own bed. My husband, my children, dog and my cats and some of my family was there. I never felt more love than that moment. My feelings of the first month home were mixed. One minute I was scared, then happy, or sad, but I always had a positive attitude and I never gave up hope. I loved being at home. My neighbors came and brought me lunches and dinners. My family was always visiting. Everything was so wonderful.

February, I went back to the hospital for more chemotherapy. It was given to me two times a day every other day for 3 days. I would go home on Sundays which was my third day. The best part about that was Ria would come to the hospital on those days and sit with me until I was able to go home. The rest of that month went smoothly.

March I was back in for the same old thing. Ria was with me until I could go home on Sunday as usual. At this time I would have to go to the cancer center at the hospital three times a week for blood tests and also a shot to re-grow my bone marrow. On March 12 we got a new dog named Valentino. It was just what I always wanted, a small cuddly dog. Later that day I felt warm so took my temperature. It was 101.2 degrees. And here it goes, I called the doctor and back to the hospital for who knows how long. Well I ended up with pneumonia and I was in the hospital for a while. I have no white blood cells at this point because of the chemo so I have to rely on the

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My Story (from page 3)

medicine they give me. I was there for six weeks and for most of that time I had a fever of 102 and 103 degrees. I was even in the hospital for Easter. I enjoyed it though. We had Easter dinner in my room. My daughters even came and colored eggs in my room. Even the nurses came in and joined the party. Debbie came too, and she thought of everything. She brought ham, scalloped potatoes, veggies, salad and my favorite, chocolate cream pie for desert. Soon after desert I had to ask everyone to leave, I could tell my fever was going up and I was really tired. I was finally able to go home on April 10th. I had no more fever, no pneumonia, I was very weak but it felt good to go home.

The feelings that I had at this time were plain and simple. I thought I was going to die. I knew how close I was but somehow I kept going, I kept fighting and it worked. My father is gone but his words still stay, "Never give up no matter what, you can get through anything."

April, May and June chemo was still three times a week. Only these months I only spent a week extra in the hospitals, after the chemo week, with staph infections. The IVs they gave me took care of that in quickly. In June I had to have the Hickman removed since that was the cause of the staph infections. My nurse practitioner was with me, that was a hoot. They had to bring us a bucket because we weren't sure which one of us was going to throw up first because the infection was so bad. We made it through it and laughed for a long time about it.

These three months were aggravating. I was in and out of the hospital and I just wanted to move in and stay there. In other words I was very tired of the whole mess. I was also over joyed and very thankful for remission. I was so glad this was finally over; I felt like running out of the hospital hoping to never have to return. Well ok I still had to go back for monthly blood work, but I was okay with that. But the leukemia was gone and that was all that mattered.

In July of 2009, I went in for a routine blood test. On July 20th they called, they said my white blood cell count was high and I needed another blood test and a blood smear. So off to the cancer center we were once more. I took John, and Debbie and it was what felt like the longest hour of my life. Finally, it's show time. I was called in to the doctor's office. He said those words I was never hoping to hear, "Maria, your leukemia is back." I started to cry and I swear at this time I wasn't even listening to him. I got up and I walked to the bathroom and I started getting sick. I came out of the bathroom and both the doctor and the nurse practitioner was there and John and Debbie. We all had a big group hug and cried. We turned into such a family there. On Thursday, I had to go back to get a bone marrow test done, that really hurts. On that Friday, I had to get another Hickman put in and we started another round of chemo. I was luckily able to go home after the treatments and they were only for a week at a time.

I was very sad that the cancer came back. Once again I was on the phone making phone calls to my friends and family. This time I had to call my oldest brother, Ralph. He was the hardest person to call. Ralph was my perfect match and I told him only to do this because you want to, not because you have to. I can't even explain the feelings that I had at that moment but I know I was jumping for joy when he said that one word, yes. It was the best word I have ever heard. All I know is that I did this once and I can do it again, I will win this fight.

August 2009 was a very long month. I had to have two more bone marrow test. I will never do that again while I am awake. I had to get a lot of platelets and red blood cells. I even had to go to the dentist to see if there was any underlying infections we didn't know about, and little did I know, there was. It had to be the tooth that I had a root canal and a permanent cap on it, just my luck.

September 1, 2009, I finally got the call I was waiting for. Off to the hospital again, this time Strong. It was time to prepare for the transplant. We got started on September 2nd. Ralph was on his way. As I was getting the chemo, he was getting shots so his body would make more bone marrow. This was the easy part. On September 8th, Ralph went to the phoresis lab and I was in my room. Ralph was put on a blood machine that was hooked up to both of his arms. The machine took the blood from one arm took out the stem cells and put it back through the other arm.

When that was all completed the Red Cross cleaned and conditioned the stem cells and sent them to my room. Of course I laughed when they came in and I saw that I had my own cooler. The process of receiving them was a big letdown. The nurses gave me liquid Benadryl to fight off any allergy. I ended up sleeping through the whole thing. But it worked, and I was back in remission. Little did I know what lied ahead.

When I went home, I thought I had *conquered* the world. It just was very hard to get there. I was very weak and just so very tired all the time. I slept all of the time, whenever I wanted. I slowly but surely was able to start doing more around the house. I was feeling better and better every day. All I could think about was that I did it! I won! I fought cancer and I won!

In May of 2010, I had a very wonderful mother's day. Three days later my cat passed away in my arms, and the very next day I started getting sick. By Saturday, I couldn't walk and was very weak with a fever of 102 degrees. Of course, back up to the hospital to see what is going on. I was told that it was Graft vs. Host Disease. I had to get a colonoscopy and what I like to call a mouthoscopy (endoscopy). With these tests they were able to see my stomach and my colon (long intestine). They looked like downtown Baghdad. The next phase to help with the disease was to put steroids in through my groin and to my stomach and colon. This was very hard and it made me very weak. I could not walk on my own.

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My Story (from page 4)

I needed help with everything. I stayed in the hospital for about four more weeks till I was able to go home. I missed a few weddings and parties at this time, but I did it.

This was very hard on me and I was starting to feel like I wanted to give up. I just wanted to go to sleep and never wake up. While I was still in the hospital the doctor gave me a day pass so I was able to go home for a little bit on that day. That gave me the will to fight, to win yet again. When I finally went home from the hospital after everything, they had to put a bed in my dining room. I didn't care though; I finally made it home after all of that.

December 2011, things got bad once more. The DVHD started to affect my eyes and muscles. We decided at this point to start photophoresis treatments. This was working very well and helping a lot with my eyes and my muscles. October 2012, things got even worse and landed me in bed for four days. No light, no TV, and no computer. My muscles started up again, which is not fun. I even started to retain water and I could not figure out why.

November 2012, well what can I say, I always said no more chemo and here I am again. But right now I have no other choice. They tell me that it is very mild and I won't lose my hair or anything like before. But the fear is still there. The treatments are once a week for who knows how long on Friday's. The GVHD has even hit my teeth and now I need to go to a specialist to get them taken care of. All I think about is that I can do this; I am not going to lose this. I am going to win and kill this GVHD.

December 10, 2012 I had the worst side effect ever. I had a heart attack. They put a stent in and two days later I went home. I still have a hard time believing it was a real heart attack. This has all made me very nervous and so very tired but I still want to fight. I have so much on my plate, from school to doctors' appointments and now treatments. I sometimes don't know if I am coming or going. It's so hard to keep everything in line, not to mention my family that needs me. All I think about is that I can do this, God doesn't give you too much to handle. I am just so thankful for all of the support that I have had behind me. To all of my friends and family, even the people at my school. Everyone has been so helpful and caring throughout this whole thing and I don't think I would have been able to make it through without all of those people at my side.

Support Group Meetings

"OPEN AIRWAYS" - LUNG Gathering Group Thursday, October 17 at 12 noon.

Winfield Grill - 647 Winton Rd. Rochester, NY
(Between East Main St and Browncroft Blvd.)
- and -

Thursday, November 14 at 12 noon.

Hicks & McCarthy - 23 S. Main St. Pittsford, NY
(1 week earlier)

HEART Transplant/VAD Support Group Thursday, October 10 at 6:30 p.m.

Finger Lakes Donor Recovery Network
- and -

Wednesday November at 6:30 p.m.

LVAD specific support group. Location per future announcement.

All Heart Transplant/VAD Meetings are held at the seventh floor conference room near the 7-3400 Corridor unless otherwise indicated.

United Network for Organ Sharing

Candidates listed as of 9/18/2013

97,670	Kidney
15,801	Liver
3,573	Heart
2,063	Kidney/Pancreas
1,626	Lung
1,174	Pancreas
253	Intestine
49	Heart/Lung

119,694 **TOTAL**

Total may be less than sums due to patients in multiple categories

www.unos.org

Save the Date . . .

Finger Lakes Team Halloween Party and Casino Night

Saturday, October 19

Moose Lodge 8 - 11 P.M.

5375 W. Henrietta Rd.

West Henrietta, NY 14586

Tickets are \$25.00 and include: "Gambling Money", DJ, Photo Booth and appetizers.

There will also be a Prize Raffle, 50/50 Raffle and Prize for Best Costume.

To purchase tickets or for more information, contact: Tanya Herrold at (585) 705-2515

Come support Team Finger Lakes (sponsored by the Finger Lakes Donor Recovery Network) as they head to the Donate Life Transplant Games of America in July, 2014.

ROC the Day

Wednesday, December 11

Please mention to your co-workers and friends that they can make a one-time donation to TAO via the United Way by using our number (2493).

TAO Annual Holiday Party

Saturday January 11, 2014

Joey B's, Packett's Landing, Fairport, NY.

(Handicap accessible)

12 Noon - Social hour

1:00 PM - Dinner

\$15 per person with TAO underwriting part of the cost.

Important: **RSVP by January 4 by sending a check with names and the number of people attending to TAO, PO Box 23552, Rochester, NY 14692-3552.**

Check out Facebook and the TAO website for up to the minute details.

Shopping at Amazon?

TAO can benefit from your purchases this holiday season. Simply go to www.tao-rochester.org and click on the Amazon widget and do your shopping!

Don't forget to visit and like our Facebook Page



www.facebook.com/

SHARE IT WITH OTHERS

Join a Committee

Sunshine, Newsletter,
Membership, Awareness
Interested?

Call **1.888.664.1463**



**Flu Season is approaching.
Get Vaccinated!**

Wishes of Wellness To

Our healing thoughts and prayers go out to:
Bernice Eblovi, Kathy Wesline, Norm Breen, Joe Heil and
Carol Marie Pfuntner

Transplant Anniversaries

Donna Crosby	Liver	November	2003
Peter Davis	Liver	November	1996
Bob Munn	Liver	November	2010
Daniel Phillips	Liver	November	2009
Jerry Runion	Kidney	November	1994
Alice Sceusa	Liver	November	2002
Michael Stelljes	Liver	November	2001
Mike Swete	Liver	November	1995
Eric Wright	Double lung	November	2006
Susan Bennett	Kidney	October	1998
Bernard Blocchi	Liver	October	1996
Claudia Ciresi	Liver	October	1994
Michelle Halloran	Kidney	October	1997
Dave Johnson	Liver	October	2000
Dennis Kovel	Kidney	October	2001
Louis Latorre	Liver	October	2007
Bob Legge	Kidney	October	2009
Thomas Murphy	Liver	October	2009
Keith Oliver	Liver	October	2002
Carol Pfuntner	Kidney	October	2001
Carrie Rodriguez	Kidney/Pancreas	October	2005
Mary Stein	Liver	October	2005

Tops Never Stops

Tops cards help TAO raise money.

The Tops Gift Card Program allows our nonprofit organization to earn a 5% return by selling Tops Cards.

The more we sell, the more we earn.

The cards are available in \$25s, \$50s and \$100s.

Transplant Times

Submission Deadline

**For December 2013/ January 2014 issue:
November 4, 2013**

**Articles /ideas email to:
auggieday@aol.com or send by mail to:
TAO, PO Box 23552, Rochester, NY 14692-3552**

Contributions

We wish to acknowledge and thank the following individuals and / or organizations who made contributions to TAO.

Donations:

United Way:

Laurie Albert
Claudia Ciresi
Karen Cretella
Tracy Clingerman
Malik Day
Nancy Dohm
Sandra Felo
Vincent Grillo
Autumn Hale
Michael Kerins
Daniel Nowak

In Kind:

Sue Cimacata

If we omitted you, please let us know so that we may post in the next issue. **THANK YOU.**

Gift IDEAS

A contribution to TAO in honor of or in memory of a loved one, special person or relative is always a thoughtful gift. It is a gift of caring that you can give on any occasion - a birthday, an anniversary or a special holiday.

Please make your check payable to:

Transplant Awareness Organization

Mail to: TAO, PO Box 23552

Rochester, NY, 14692-3552

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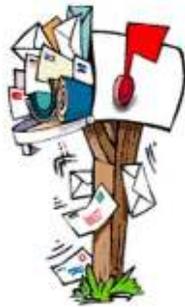
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TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES: \$20 Family \$100 Institution New Member Renewal Date unable to make dues payment at this time

Extra contributions to help our organization are always welcome, and are tax-deductible. Make checks payable to: TAO of Greater Rochester, PO Box 23552, Rochester, NY, 14692-3552.

Name (please print) Spouse/companion

Address City State Zip

Phone () E-mail

- Candidate Recipient Family Member Donor Family Friend Professional

Candidate/Recipient information: # of Transplants Hospital

Date(s) Organ(s)/Tissue(s)

If you do not wish the date of your transplant to be published in the Transplant Times each year on your anniversary date, please check.