



Transplant Times

June/July 2016

A newsletter of the Transplant Awareness Organization of Greater Rochester

www.tao-rochester.org | 1.888.664.1463

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Membership Meeting

Guest Speakers / Topic

June 20, 2016
Picnic
details on pg. 4

July 2016
No Meeting!
Enjoy the summer!

A Message from the President

As summer approaches, transplant recipients have to deal with issues such as the sun. Even though sunscreen should be worn every day, it's even more important during the peak of summer. Please be aware of any changes on your skin, any mole that changes color or size and don't hesitate to have it checked out. Get out and enjoy but protect yourself!

One way to enjoy the start of summer is to attend the annual TAO picnic. The details are in this newsletter. Come out and meet other members, enjoy some good food and celebrate life!

We will not meet in July and August but the board will be busy planning future meetings and events.

The River Run was a success, raising over \$30,000 for the Patient Transplant Fund with over 900 participants. TAO was proud to be a sponsor of such a great event!

The Donate Life float in the Lilac Festival Parade was a great success on Saturday, May 7. The float helps spread awareness for organ, eye and tissue donation and transplantation.



Some of TAO's members are headed to Cleveland for the Transplant Games. We wish the athletes safe travels and good luck in their events and look forward to seeing the gold medals!

On behalf of the membership and the TAO board I'd like to thank Geoff Foley for his years of service on the TAO board, holding the office of president and managing the TAO website. Geoff has decided to step down from the board. We wish him all the best and most importantly good health and hope to see him at future meetings and events. Thank you Geoff!

Debbie Gendrzewski

TAO Meets

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

Visit & like our Facebook Page
www.facebook.com/TaoOfRochester



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TAO Providing support, understanding, education & resources . . .



How and why CaringBridge started, and how the organization grew

By Sona Mehring

The question usually goes, *"Which comes first, the chicken or the egg?"* But in my case, it was the chicken feed. Back in the early 1990s, I had landed a good client – yes, a poultry association – for Beacon Point Technologies, the consulting company I had founded. The project was to write a program to manage chicken-feed inventory. It was a big contract, and with three growing boys under my roof, I appreciated the work. But in the midst of coding, I lost momentum. I remember asking myself, *"What am I doing with my skills? With my life?"* I completed the assignment, on-time and under-budget, which is always a point-of-pride for a consultant. But the chicken-feed image started scratching in my head: *"What can I do that matters more?"*

I had felt this way before. When I enrolled as an undergrad at the University of Wisconsin-Eau Claire, the plan was to become a nurse like my Mom, Bonnie. But her path – turns out – was not my path. In the college careers office, I ran my finger along the laminated job placement and salary chart. In the top-right quadrant, indicating careers with considerable opportunity and compensation, I saw: "Computer Science." That became my major. I loved it from the first minute.

Among my earliest experiences using technology to "make something to help people" was when a geology professor at Eau Claire hired me to create an easier way to administer multiple-choice tests. I will always remember the sense of satisfaction in simplifying a task that was complicated and time-consuming for him. That feeling of accomplishment stuck with me, as clearly as the chicken-feed image. Today, I might call this foreshadowing, but I truly never imagined how my skills would eventually build something so meaningful and impactful.

It happened in June 1997, when my dear friend, JoAnn, was hospitalized with a life-threatening pregnancy. I asked her husband, Darrin, how I could help. Overwhelmed and exhausted, he said, *"Just let everyone know what's going on."* After a few agonizing calls, I scanned the long list of people who needed to be contacted and thought, *"There's got to be a better way to keep people informed."* My software engineer-self kicked in, and in a matter of hours, I created a website where I could post regular updates,

and where family and friends could leave messages in a guest book.

On June 7, 1997, the day baby Brighid was born three months premature, the first CaringBridge website was also born. Sadly, after a nine-day struggle against tremendous odds, Brighid died in surgery. I posted the news on Brighid's website, along with a message from JoAnn and Darrin thanking everyone for their love and support. At Brighid's memorial service, a lightning bolt of Inspiration pierced my heart and soul.

Surrounded by the sea of caring people, whose waves of love and support had surged through the internet to comfort her parents and each other, I knew that rolling out CaringBridge was no longer a choice, but a calling.

I transformed Brighid's website into a stand-alone service that enabled people to easily create private, personal websites and fill in content themselves. The name CaringBridge rose organically out of *"caring for Brighid,"* and the *"bridge"* – or lifeline – of caring among patients, families and friends. Without realizing it, I had pioneered the concept of personal-health social networking.

My appreciation for the power of social support during a health journey deepened when I created websites for my 94-year-old grandma, Bessie, and my Mom, who was diagnosed with Stage IV breast cancer in 1998. I reactivated Mom's site three years later, as liver cancer swept her away. Up until 2001, I had approached CaringBridge as a personal, pro bono community service. But with a nudge from a founding board member who said, *"Jump and the net will appear,"* I fully committed to CaringBridge. I confess I made the leap without a proven revenue model, but thanks to a growing number of dedicated volunteers, we generated enough charitable donations to become a self-sustaining, registered non profit by 2002.

Today, every 7 minutes a new CaringBridge website is created, and we just marked our 2 billionth visit. Nineteen years of milestones are captured on a CaringBridge History Map in our office, beginning with Brighid's birth, and up to research under way to measure the power of social support on health outcomes. The map reminds me that bringing love, hope and compassion to those on a health journey matters more than chicken feed ... unless you are a chicken. I recently traded my CEO hat to serve as chief ambassador for CaringBridge. And while my heart may always secretly – and not so secretly – beat for technology, I am thrilled to be sharing with people around the globe the legacy of Baby Brighid's love.

Sona Mehring is founder and chief ambassador of the global nonprofit organization CaringBridge.org, based in Eagan, MN, and author of "Hope Conquers All."

Community applauds Donate Life float in Lilac Parade

This year was no different than others when the Donate Life float passed by hundreds of people standing along the street at this year's Lilac Festival parade on Saturday, May 7. The applause and shouts of "I'm a donor" from the crowd was overwhelming. For those riding on the float, it was evident that the community supports organ, eye and tissue donation.

Each year, the Lions Eye Bank at Rochester coordinates the float entry with support from Transplant Awareness Organization. This year, the spacious flatbed was generously provided by TAO members Tom (liver recipient) and Lori Lane.

Earlier in the morning float riders gathered for a tailgate breakfast; then were transported to the parade line-up to begin transforming the flatbed into a colorful, eye-catching decorated float. Signs held by every rider indicated their personal connection to donation and / or transplantation. As those along the parade route read the signs, a look of awe came over their faces. It wasn't uncommon for a parent to turn to their child and begin explaining what the Donate Life float was all about.

The purpose of participating in the parade is to show the community that transplantation works. It is also a time to remember and honor organ, eye and tissue donors.

Several TAO members, many of which volunteer with the Lions Eye Bank at Rochester, have been participating and riding on the float for many years.



Traveling Overseas while on Dialysis

Most dialysis patients are aware that they can travel in the U.S. and receive dialysis treatment from other locations in the U.S. by searching on www.dialysisfinder.com. However, did you realize that there is a way to travel outside the U.S. and still receive your treatments?

Freedom the Dialysis Holiday Specialists are the UK's first and only travel company that specializes in arranging holiday dialysis for kidney patients. They have been organizing patients' treatments for over 26 years. They have over 50 units in 25 countries worldwide, and along with land based holidays they offer both ocean and river cruising opportunities. The dialysis units they use have all been screen to ensure that they use Universal Precautions while performing dialysis. They use a mix of private and public dialysis centers and welcome English speaking patients.

Their website is www.holidaydialysis.co.uk. They can be reached by emailing ifo@holidaydialysis.co.uk, or by calling +44 01509 815999



Thank you for voting! Your vote mattered! We are pleased to announce that Sue Muto, kidney donor and Erin Collins, kidney recipient were elected to the board. Also Linda Barnard, wife of a heart recipient, Bev Shank, liver recipient and Norm Breen, heart recipient were re-elected to the board. Geoff Foley has stepped down from the board.

Shopping at Amazon?

TAO can benefit from your purchases. Go to www.tao-rochester.org and click on the Amazon widget to do your shopping!

community events Save the Date . . .

Monday June 20, 2016

TAO ANNUAL PICNIC

To be held on Monday JUNE 20 at the Lodge @ Buckland, 1341 Westfall Rd. (between Winton Rd and Clinton Ave, same place as last year) in Brighton. Catering the event will be DINOSAUR BAR-B-QUE.

The event will begin at 5:30 pm and dinner will be served at 6:00pm. The cost will be \$13.00 for Adults and \$6.50 for Children. To make reservations please contact Bev Shank at 244-1536.

Make checks payable to:

Transplant Awareness Organization and mail to:
Bev Shank, 75 Eastland Ave. , Rochester, NY 14618

COME AND JOIN US!

United Network for Organ Sharing

Candidates listed as of 5/13/2016

100,005	Kidney
14,772	Liver
4,120	Heart
1,909	Kidney/Pancreas
1,439	Lung
996	Pancreas
269	Intestine
41	Heart/Lung

120,746 TOTAL

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

www.unos.org

transplant Support Group Meetings

"Open Airways" - Lung Gathering Group

Thursday, June 16 @ 12 noon

Jeremiah's
Rt. 250, Fairport Nine Mile Point Rd., Penfield

Thursday, July 21 @ 12 noon

Corner Bakery Café
3300 Monroe Ave. Pittsford

Heart Transplant/VAD Support Group

Thursday, June 9 @ 6:30 pm

Transplant Awareness Organization

Thursday, July 7 @ 6:30 pm

LVAD Specific Support Group
ACF A & B Conference Room (Above Main Lobby)

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

Transplant Times

Submission Deadline

**For August-September 2016 issue:
July 7, 2016**

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

Board of Directors & Officers

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Karen Guarino

Bonnie Haefner

Amy James

Judy Munn

Sue Muto

Janice Odenbach

Karen Porterfield, LMSW

Transplant Anniversaries

Tiffany Conboy	Kidney	April	2014
Jerry Stephenson	Liver	April	2016
Kirk Wilson	Liver	April	2016
Thomas Clark	Kidney	June	2007
Bernice Eblovi	Liver	June	2002
Sheldon Kristin	Kidney	June	2014
Kevin McCorry II	Bone Marrow	June	2004
Dick Miller	Heart	June	2007
Shawn Pangburn	Liver	June	2011
Larry Rosner	Kidney	June	2014
Karen Lee Sommer	Liver	June	2006
Mike Yendrzeski	Liver	June	2002
Rick Clark	Kidney	July	2004
James Connolly	Liver	July	1990
John Dedloff	Heart	July	2011
Cindy Deshane	Liver	July	2005
Matthew Felo	Lung	July	2007
Bonnie Gottorff	Kidney	July	2005
Cheryl Helfer	Kidney	July	2002
Dean Kiefer	Kidney	July	2012
Daniel Klimek	Cornea	July	2011
John Odell	Liver	July	2010
Richard Perez	Liver	July	2003
Patricia Ridge	Kidney/Pancreas	July	2006
Philip Ronzo	Liver	July	1996
William Sprenger	Heart	July	2015
Joanne Tucker	Liver	July	2006
Giulio Verde	Heart	July	1998

TAO www.tao-rochester.org

**G
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To act as a support group for transplant candidates, transplant recipients and their families.

To provide education and information on transplantation issues that surround it.

To promote organ and tissue donation awareness.

All potential transplant recipients, candidates, family and friends are welcome. Meetings are held monthly and include programs of interest to the transplant community.

Our Sympathies

Bonnie Haefner and Family on the death of her brother, Jimmy

Delores Metzger on the death of her husband Leonard

Paula McKay's family, Paula passed

Wishes of Wellness

Our healing thoughts and prayers go out to:

Dave Spiro
Bonnie Haefner
Geoff Foley
Laurie Packard



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, \$100s .
Contact Bonnie Haefner at (585) 391-3555

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: TAO

Mail to: TAO
PO Box 23552
Rochester, NY, 14692-3552

March meeting : Theo Munson talks about Grief



Theo Munson receiving a certificate of appreciation from TAO President Debbie Yendrzeski after presenting to the membership.

And the winner of the Donate Life Blanket is... Debbie Dunn! The drawing was held at the River Run.



MAPLEWOOD ROSE GARDEN

TAO now has two new rose bushes planted at the Maplewood Rose Garden in memory of past president Dennis Stenshorn and former treasurer Kathy Wesline. Kathy was a lung recipient and Dennis was a heart /lung candidate.

To visit the rose bed, it is right near the small gazebo and to the left of the large gazebo. There are benches near by that one can sit on and reflect . The park is located on Lake Avenue.



A special thanks to Wambach’s Garden Center for donating one of the rose bushes.



Wambach’s Garden Center
2590 Culver Rd \ Rochester, NY 14609
(585) 342-7120

Rochester River Run

The 15th Annual Rochester River Run was held on April 17. Over 900 participants raised over \$30,000 for the Transplant Patient Fund. A very moving donor/recipient ceremony kicked off the run. TAO was well represented with runners and at a table where we handed out sunscreen.

The Transplant Patient Fund at UR Strong helps patients with needs that are not covered elsewhere.



Erin Collins and her "posse" at the Rochester River Run proudly wearing their TAO t-shirts.



TAO member Art Lisi at the TAO table distributing sunscreen to the runners who participated in this year's River Run.

Contributions

In Memory of :

Roger (Bud) Robinson
Judy Robinson

Ada Clark, Hugh Clark
Kirk & Judy Wilson

Bob & L. Marie Wilson
Kirk & Judy Wilson

Introducing New Members

Jerry and Lia Stephenson

Welcome new members, Jerry and Lia Stephenson. Jerry was born and raised in the Rochester area. He and Lia are now retired from LiDestri Industries. Jerry has undergone a liver transplant within the last month. He is doing quite well and has a very positive attitude about his recuperation process. He has two grown sons who also live in the Rochester area. He enjoys doing yard work and collecting die cast classic model cars, while Lia is a craft enthusiast. Jerry helps Lia sell her wares at craft fairs held in October through December. Once he is further along in the recovery process, Jerry is interested in contributing to getting the transplant message out to the public at health fairs or through other means.

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**Dues for your 2016 membership are now due
Help Support TAO's Mission**



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- DUES:**
- New Member
 - Renewal
 - \$20 Family / Individual
 - \$100 Business / Organization
 - unable to make dues payment at this time

Donations 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) _____

Address _____ City _____ State _____ Zip _____

Phone () _____ E-mail _____

- Candidate
- Recipient
- Family Member
- Donor Family
- Friend
- Professional
- Business / Organization

Candidate/Recipient information: # of Transplants _____ Hospital _____

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

Check here if you do not wish your transplant anniversary date to be published in the *Transplant Times*.