



Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

Providing support, understanding, education and resources for transplant recipients, candidates and their families.

May / June 2012

www.tao-rochester.org

1.888.664.1463

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Membership Meeting Guest Speakers / Topics

May 21, 2012
TBD

June 18, 2012
Annual TAO Picnic
(details on page 7)

TAO Meets

3rd Monday of the Month
Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY

A Message from the President



As I sit down to write this note for the upcoming TAO newsletter, it is April 1. April is National Donate Life Month (NDLM) - that month of the year when we especially celebrate and honor all those who have donated organs and tissues, and have thereby given life and healing to others through the miracle of transplant.

In putting this note together, I came across a quote by the poet and writer Khalil Gibran that I think can be aptly applied to the act of organ and tissue donation. It says:

"You give but little when you give of your possessions. It is when you give of yourself that you truly give."

Organ and tissue donation clearly represents the ultimate act of giving of oneself. Those like me who have been privileged to receive the Gift of Life know only too well how precious that gift has been. For my part it has meant being grandpa to new grandchildren, a witness to another child's marriage, more time spent with family and friends, and many more celebrations of birthdays and anniversaries.

This month of April is thus a month in which I shall especially reflect on how fortunate and thankful I am to my donor and his family for the gift of new lungs,

now almost seven years ago.

For all of us touched by the Gift of Life, NDLM also is a time in which to encourage others to consider enrolling as an organ donor. Great progress has been made over recent years in building the State registries of organ donors across the U.S., with more than 100 million organ, eye, and tissue donors now recorded. Despite this progress, more than 114 thousand individuals are presently awaiting organ transplants, sadly some of them to die before an organ becomes available.

Obviously more needs to be done to expand the donor registries. If you or a family member has been an organ, eye, or tissue donor, we sincerely thank you. If you are a recipient, there is no better way to give back than to encourage others to register as a donor.

Looking forward to seeing you at an upcoming TAO event!

Geoff Foley

Gluten-Free: More than a Fad

by Tricia Mathew

Background

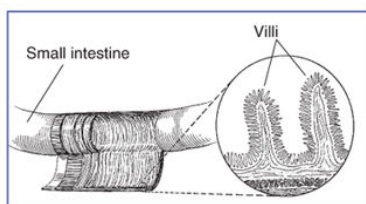
Gluten-free has become a hot topic in nutrition and health, but there's still a lot of controversy and even misinformation about what gluten-free means and why someone would follow a gluten-free diet. Some of the confusion stems from celebrities in Hollywood who have become proponents of a gluten-free diet as a weight-loss diet¹, and others who are now dismissing gluten-free as just another fad diet². Gluten-free, however, is much more than a fad diet for people suffering from different types of gluten-sensitivities.

Gluten sensitivities

There are three main types of gluten sensitivities: celiac disease, wheat allergy and idiopathic gluten sensitivity. While all three of these conditions benefit from a gluten-free diet, there are some differences in the mechanism, symptoms, severity and prevalence of each of them.

Celiac disease (also known as gluten-sensitive enteropathy, celiac sprue or non-tropical sprue) is the most well-known and studied of the gluten sensitivities, and it is characterized by chronic inflammation of the small intestine. When an affected individual consumes gluten, his or her immune system reacts and attacks the villi (areas of nutrient absorption) of the small intestine. Celiac disease was once considered a rare disorder, but is now known to be a common genetic disorder that affects more than 2 million people in the United States, or about 1 in 133 people³. The rise in cases is partly due to better diagnosis, but studies based on blood kept in storage indicate that up to 4 times more people may be affected now than 50 years ago⁴.

Celiac disease is an inherited autoimmune disorder but some individuals remain symptom-until the disease is triggered by surgery, pregnancy, childbirth, viral infection, or severe emotional stress³. There is a wide range of symptoms that usually consist of digestive symptoms in children (e.g. abdominal bloating, chronic diarrhea, vomiting, constipation, etc.) and a variety of digestive and non-digestive symptoms in adults (e.g. unexplained iron-deficiency anemia, fatigue, bone/joint pain, skin rash, canker sores in mouth, missed menstrual periods and even infertility or recurrent miscarriage). The range of symptoms makes diagnosis difficult and individuals are often misdiagnosed. There are specific blood tests, but



the only definitive test is a small intestine biopsy⁵. Proper diagnosis is important because of the vitamin and mineral deficiencies that can result when the small intestine can no longer absorb these nutrients.

A true wheat allergy is like other food allergies in that it involves an immune reaction to specific proteins found in a given food, and it has symptoms that may include respiratory reaction (such as wheezing), skin rashes, or gastrointestinal distress⁶. Wheat allergies are thought to affect less than 1 percent of infants and even fewer adults as many outgrow the allergy by three years of age.

Idiopathic gluten sensitivity (IGS) is the condition that we know the least about, and the name indicates that the cause is unknown. IGS usually involves neurological symptoms as opposed to allergic reactions or gastrointestinal distress, and usually individuals who show symptoms of gluten sensitivity but test negatively for celiac disease and wheat allergy are put in this group.

What is a gluten-free diet?

Unfortunately there is no cure for these conditions, but symptoms can be managed by following a strict gluten-free diet. Gluten is a protein found in wheat, rye and barley, and avoiding these foods may seem straightforward, but is complicated by the fact that gluten is often a "hidden ingredient" in many sauces, marinades, gravies, salad dressings, soups, prepared meats (hamburger patties, deli meats, hot dogs), candy, flavored coffees and teas, as well as some medications and nutritional supplements⁵. For a more detailed list of foods to avoid and question, Shelley Case's "Gluten-Free Diet: A Comprehensive Resource Guide" has become a trusted authority.

What are some nutritional concerns with the gluten-free diet?

While there are now a variety of gluten-free grains, flours and processed foods that can help fill in some of the gaps in a gluten-free diet, there are still some nutritional concerns. Gluten-free alternatives tend to be lower in iron, B vitamins and fiber and are not always fortified. It is important to work with a dietitian or doctor to assess the nutritional adequacy of your diet if you are restricting gluten.

1. Jio, Sarah. "The New Healthy Eating Fad: Going
2. Gluten-Free When It's Not Medically Necessary." *Glamour*. 9 April 2010. Accessed 19 October 2011. <www.glamour.com/health-fitness/blogs/vitamin-g/2010/04/the-new-healthy-eating-fad-goi.html>.
3. "The Gluten Free Fad: Friend or Foe?" Gluten-free Hub.

Continued on page 3

Gluten-Free (continued)

19 April 2010. Accessed 19 October 2011.

<www.glutenfreehub.com/the-gluten-free-fad/>.

1. "Celiac Disease." National Digestive Diseases Information Clearinghouse (NDDIC), NIH. September 2008. Accessed 19 October 2011.

<digestive.niddk.nih.gov/ddiseases/pubs/celiac/celiac.pdf>.

2. Katz, David. "Is Gluten-Free Just a Fad?" AOL Healthy Living. 25 July 2011. Accessed 19 October 2011.

<www.huffingtonpost.com/david-katz-md/gluten-free-diet_b_907027.html>.

3. Case, Shelley. "Gluten-Free Diet: A Comprehensive Resource Guide." Saskatchewan, Canada: Case Nutrition Consulting Inc, 2008. Print.

4. Melina, Vesanto et al. *Food Allergy Survival Guide*. Summertown, TN: Healthy Living Publications, 2004. Print.

Shopping at Amazon?

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



Dental Implant Surgical Center

Dr. Mary Ann Lester, DMD
1815 Clinton Ave. South Suite 510
Rochester, NY 585 473-7653

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.

United Network for Organ Sharing

Candidates listed as of 4/24/2012

91,994	Kidney
16,048	Liver
3,151	Heart
2,148	Kidney/Pancreas
1,618	Lung
1,270	Pancreas
277	Intestine
52	Heart/Lung

114,018 TOTAL

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

www.unos.org



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Denny Biller's Story

In August of 2005 I began a journey that would be like no other. It would bring myself and my family tears of despair and of joy. It was when I was admitted to the Heart Transplant program at URMC. Talk about emotions. They were working overtime. Each day would bring a new round of tests. I hoped each one would keep me in the program. Every day finds my wonderful wife spending every waking moment with me. I don't know how she did it. There were plenty of days when I was not very good company, but she was always there, telling me to hang in there. Reminding how much I had to live for.

When I found out that the test results were complete and I was eligible for the program, I was thrilled. Except for one little thing, my gall bladder had to come out before the transplant. That was no picnic, but had to be done. Little did I know that the waiting would be the hardest part. Each day, I would think, is today the day? Nope! Let's see, how many gallons of blood will they draw today?

What's on the menu? Oh Boy, meatloaf! Yuck! What's on TV? One of our friends brought in a portable DVD player and a bunch of movies. It sure helped to keep me occupied. Scrabble games with my wife. All our wonderful friends who visited so often always helped to brighten the days. When the staff told us we could bring food from home that was the best news yet. Speaking of the staff, where did they find all those wonderful people? To this day I thank God for the staff of 7-3400.

Time is really dragging now. It's late September and I've been here almost 2 months. There have been hearts offered, but none that were acceptable to my doctors. 2 more became available, but went to people in greater need than me. I don't know how much more I can take. I have decided that if I haven't been transplanted by time the holidays arrive, I'm going home. I kept this to myself, not wanting to upset my family.

My son talked my wife into taking a hospital break to play with the grand kids and he would take over the hospital duty. About 7 that evening, Dr. Chen and Mary Beth walked in and gave me the news I had been waiting for! They had a heart for me! My emotions broke through and I cried. My son hugged me and I cried some more. The nurses came in and hugged me and I cried some more. When my wife arrived I cried some more. I guess I didn't realize how much I had bottled up inside. That was October 5, 2005 a day I will never forget.

Post transplant recovery took longer than we had hoped. I was really anxious to get home. I had been there 1 week short of 3 months. When the last hurdle was crossed and it was time to go, I realized I was leaving my new family behind. So my discharge was bittersweet. But it was time start living again.

Home, Wow it's so good to be here. My son and my sister-in-law have been scrubbing and bleaching every nook and cranny in the house. The risk of infection is on every one's mind. It seems like most of my day is spent taking meds. If I'm not taking meds, I'm eating. I lost 45

pounds while I was in the hospital, none of my clothes fit. The steroids have kicked my appetite into high gear. I'm always hungry. I'm shaking so bad from the Tacro I can't even write. I'm walking and exercising and getting a little stronger. I can't believe how weak I am.

We go back to Strong for our scheduled biopsies. Now there's a real treat for you. Just lay down on this table while we poke a hole in your neck. Then we're going shove this wire thing down into your heart so we can chop out little pieces of it! As it turns out, it's not as bad as it sounds. It's scary at first, but it's necessary, so you just do it. The staff in the cath lab is super. They know you're scared and they do everything they can to help you relax. Your biggest fear is, am I rejecting? I was fortunate I was never in that position. Each time I tested positive they reduce my immune suppressants. Wow this is great. I can pick up a cup of coffee without spilling it. Maybe it's time to put the sippy cup away! But I'm getting stronger and I can do more things for myself. Life is returning!

My wife Lee had met Chris Arcara while her husband Tom and I were in Strong. Tom and I went back to back for our transplants. We all became friends and shared our experiences, good and bad. Tom and I always asked the same question, why us? How come we survived? How do we pay back all these wonderful people? That's how "The beat goes on" was born. It energized us. It gave us a purpose. It made those times more bearable.

As more and more meds were reduced I became more like my old self. I gained some weight. I got off the insulin. What a plus that was. I was beginning to feel like a pincushion. So here I am almost 7 years out. We've moved to Florida and we play golf at least twice a week. There's not much I can't do, as long as the rest of my body cooperates. I still check in monthly to get the results of my blood work and for my annual check up. So I have not lost touch with the wonderful people in the transplant unit.

Anyone entering the program can rest assured that they are in the best of hands.

Life is Good!

Transplant Times

Submission Deadline

**For July /August 2012 issue:
Monday, June 4, 2012**

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

Looking for Help with Redesign of the TAO Website

As an organization, TAO's ability to serve our members, and the transplant community in general, requires us to have first class ways to communicate - especially through our newsletter and our website.

The TAO board believes our website needs major improvement. We would like to put together a new TAO website which is a better source of information for our members; it should be more visually interesting and offer content that is informative, current and helpful to our members and those who visit. Unfortunately, the TAO board itself lacks the skills required to develop an improved site. We wonder therefore, whether any of you among the membership have good web authoring skills and would be willing to donate some time to help us redesign our website.

If you have such skills and would like to volunteer your time for a good cause, please contact Geoff Foley (geoffF21@yahoo.com) or Debbie Yendrzeski (auggieday@aol.com). Thank you!

Are you interested in becoming more active in your organization?

Have you ever thought about becoming a member of the Board and being active in shaping your organization? Now's the time to get involved. Elections are rapidly approaching and we are looking for new Board members. The Board meets once a month prior to the general membership meeting. There are some activities and responsibilities outside of the board meeting that entail some time.

TAO is looking for committed people that are willing to get involved and work to keep the organization viable. Please contact your president, Geoff Foley if you are willing to be nominated for a board position.

Board of Directors & Officers

President	<i>Linda Barnard</i>
<i>Geoff Foley</i>	<i>Chris Barry MD, PhD</i>
<i>GeoffF21@yahoo.com</i>	<i>Norman Breen</i>
Vice President	<i>Matt Felo</i>
<i>Debbie Yendrzeski</i>	<i>Karen Guarino</i>
Treasurer	<i>Bonnie Haefner</i>
<i>Kathy Wesline</i>	<i>Rob Kochik</i>
Secretary	<i>Janice Odenbach</i>
<i>Bev Shank</i>	<i>Karen Porterfield</i>
	<i>Jerry Runion</i>

Transplant Anniversaries

NANCY THOMPSON	LIVER	May	1993
CAROL COMFORT	KIDNEY	May	1994
ROGER DURYEA	KIDNEY	May	1995
BONNIE PATTEN	LIVER	May	1995
AMBER CASTLE	KIDNEY	May	1999
PATRICIA BIANCHI	LIVER	May	2002
BARBARA ROBIDA	LIVER	May	2002
PHIL SINAGUGLIA	KIDNEY	May	2004
NORMAN BREEN	HEART	May	2007
MARILYN ISENBERG	LIVER	May	2007
MIKE YENDRZESKI	LIVER	June	2002
BERNICE EBLOVI	LIVER	June	2002
KEVIN MCCORRY II	BONE MARROW	June	2004
MATTHEW FELO	LUNG	June	2007
DICK MILLER	HEART	June	2007

Contributions

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

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

In memory of Frank Imburgia

Priscilla Imburgia

A Year of Firsts

(From URM Kidney Transplant News)

Paired Exchange Program

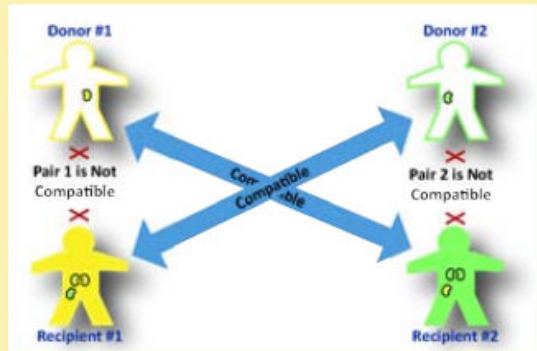
We entered our first pair into the UNOS Kidney Paired Exchange Program. The United Network for Organ Sharing (UNOS) launched its new Kidney Paired Donation Program, which contains pairs from across the nation.

We are also entering into the National Kidney Registry, another paired exchange program — you may have heard about them earlier this year when they did the largest chain in the US — 30 people received kidneys from 30 living donors.

Our goal is to offer the most comprehensive service options to our recipients both with and without living donors. If you had a living donor who was evaluated in the past and found not to be a donor for you because he/she was incompatible, please have the donor call our office if the person is still interested in donating.

Paired Donor Exchange Example

Donor and Recipient #1 are not compatible with each other. Donor and Recipient #2 are not compatible with each other. Donor #1 is compatible with Recipient #2 so Donor #1 donates a kidney to Recipient #2. The same occurs with Donor #2 and Recipient #1.



ABO Incompatible Program

We performed our first ABO Incompatible Transplant earlier this year. This successful transplant gave the recipient another option for transplantation. The ABO incompatibility program provided another opportunity for a recipient to receive a transplant from an incompatible living donor. Using a process called plasmapheresis, the antibodies that would otherwise destroy the ABO incompatible organ are removed from the blood. ABO incompatible transplants have been very successful and provide another option for potential transplant recipients. Not all pairs will be candidates for this program. Additional blood testing is required to see if you qualify. Please call our office if you would like to be tested for this program **(585-275-7753)**.

Altruistic Donor

A kidney from an altruistic anonymous donor is assigned to a recipient on the waiting list just as we would assign a kidney from a deceased donor: in order of waiting time, match, and blood type. This means that people who are waiting and do not have an identified living donor could receive this incredible gift from a generous stranger.

We were very fortunate before the new year to transplant such an amazing gift—a living donor kidney from a complete stranger.

Guest speaker **Dr. Aizhong Li** discusses the topic of Acupuncture, its theory, practice and benefits at the February TAO meeting.



Save The Date . . .

Need Riders for Annual Lilac Festival Parade

Saturday, May 12, 2012

9 a.m.- 12 noon

Once again the Council for Donation of Organs and Tissues (C-DOT), of which TAO is a member agency along with nine other organizations, will be participating in this year's Lilac Festival Parade with a float.

Transplant recipients, donor family members and living donors are needed to ride on the float. This is an opportunity to show the community that transplantation works, to thank all those individuals who support organ, eye and tissue donation and to remember all donors and their families.

Those interested please contact Karen Guarino at kguarino@rehpb.org or call (585) 272-7890.

And the Beat Goes On. . . . Dinner Fundraiser

Saturday, June 9 at 6 p.m.

Doubletree Hotel on Jefferson Road to benefit Harbor House.

For information and tickets contact Joan Malley at the Harbor House 585 473-1779, www.harborhouseofrochester.org or HarborHouseofRochester@gmail.com

Annual TAO Picnic

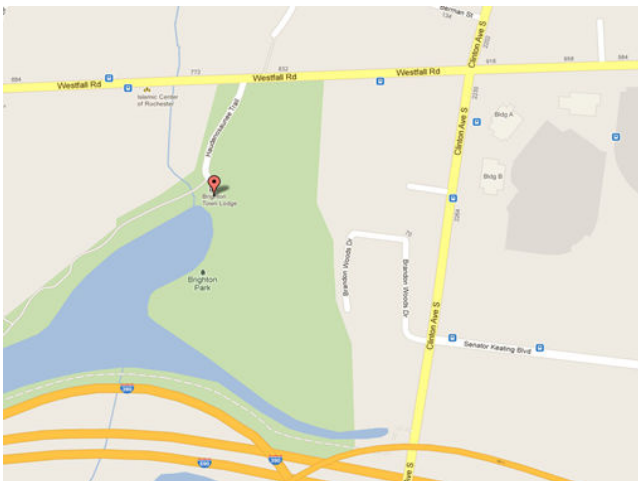
Monday, June 18 at 5 p.m.

Come one come all!

Carmen Clark Lodge at the Brighton Town Park, 777 Westfall Road (West of Clinton Ave). Picnic starts at 5:00 PM and dinner will be served at 6:00 PM.

Cost: \$12.50 adults and **\$5.00** for children.

Please RSVP by June 11 to Debbie @ 377-6028 or at auggieday@aol.com, subject: picnic



TAO Organ Specific Support Groups

"OPEN AIRWAYS" - Lung Gathering Group

Friday, June 8th Noon Mike's Diner

Monday, July 9th Noon Mike's Diner

Thursday, August 23rd Noon Mike's Diner

Contact Joanne Schum at 585-671-7635 or twoluckylungs@juno.com if interested in attending. MIKE'S NEW YORK DINER is at 3423 Winton Place (S. Winton Road Area, and Brighton Henrietta Town Line Road area)

April Euchre Tournament

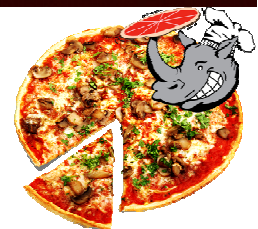
We're happy to report that the first semi-annual euchre tournament was a success! There were seven tables of enthusiastic card players, plenty of pizza, wings and veggies to eat. Perinton Pizza, Pizza Hut, Rhino's Pizza, Carmine's and Wegman's Holt Road made the dining delicious. Our president, Geoff Foley honed his skills prior to the tournament and was a fierce competitor and a good time was had by all.

A big **THANK YOU** to Matt Felo for soliciting for the pizzas and wings. Thank you to Bev Shank, Linda Barnard and Bonnie Haefner for bringing food and timing the games. We look forward to seeing more of you at future tournaments. The funds raised will be used to develop a new TAO web site.

Thank You!



Rhino's Pizzeria





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Transplant Awareness Organization of Greater Rochester PO Box 23552 Rochester, NY 14692-3552

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or Current Resident



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)