



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

Transplant Times

February - March, 2014

www.tao-rochester.org

A Message from the President

1.888.664.1463

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Membership Meeting Guest Speakers / Topic

February 17, 2014
Joe Panzarella from Astellas
Prograf and new anti rejection options.

March 17, 2014
Steven Witlin, MD
Diabetes and the Transplant Patient

TAO Meets

3rd Monday of the Month
6:30 P.M.

Christ Episcopal Church
Fellowship Room
36 South Main Street
Pittsford, NY

I would like to wish everyone a happy and healthy New Year. This is the time of year that resolutions are made, and I wish you all luck with keeping them.

In December the board held a meeting to clean up some old business and plan for the coming year. The comfort bags that will be given to transplant candidates or recipients at the hospital are complete and ready for distribution. Picture frames that TAO donated will frame selected artwork chosen from entries to a poster contest that the Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network host each year and will be hung on the transplant floor of the hospital.

There continues to be a need for more volunteers for the board and some of our committees. If anyone is interested feel free to email me @
mfelo@rochester.rr.com.

Our gift wrapping at Barnes and Noble was very successful not only monetarily but making people aware of TAO and the critical need for organ, cornea and tissue donors. I'd like to thank all those that volunteered to wrap.

Also I'd like to acknowledge all ROC the DAY financial contributors who combined gave over \$330 to TAO during the 24-hour day of giving on December 11, 2013. We appreciate your generosity.

Please join us at our upcoming meeting with Joe Panzarella from



Astellas discussing Prograf and new anti rejection options. If you have any suggestions for future speakers, feel free to let us know.

April is Donate Life Month, please consider writing a letter to the editor encouraging people to register for donation or make a commitment to promote donation in some way that you are comfortable. Nothing is more powerful than your personal story!

Keep June 16 open for TAO's annual picnic. This is a great time to meet new friends and renew past friendships. Check the website for time and location.

If you or someone you know need a ride feel free call or email us to let us know and we will try to get you to our next meeting.

I hope to see new faces at our upcoming meetings. Stay healthy and see you soon.

Matt Felo

Living with Heart Failure

Reprinted from: Advancing Care – A Family Health Publication from Highland Hospital – Summer, 2013

Heart failure can be a very frightening diagnosis, but it's important for patients to remember that the disease can be managed, and often managed very effectively. In fact, some 5 million Americans are currently living with this condition.

"When a patient is diagnosed with heart failure, our first steps are to treat their condition, but also to reassure them and help them adapt to any lifestyle changes they need to make," says Highland Hospital Chief of Cardiology J. Chad Teeters, M.D.

"Fortunately, today we have more resources than ever before to help patients: from advanced technology to diagnose the disease, to medications that help prevent or treat symptoms, to new care processes that help patients transition from the hospital to their homes safely and comfortably."

What Is Heart Failure?

Heart failure occurs when the heart muscle weakens and is unable to circulate enough blood to meet the body's needs, often causing shortness of breath, fatigue and leg swelling. When fluid builds up, the condition's called congestive heart failure. The disease usually develops slowly, often as a result of an underlying heart condition, such as coronary artery disease, high blood pressure, damaged heart valves, a congenital heart defect or arrhythmia. Heart failure may also arise as a complication of a heart attack.

Although heart damage is often irreversible, many heart failure treatments can strengthen the heart and improve symptoms. Medications like ACE inhibitors and diuretics to treat high blood pressure and congestive heart failure can help patients live longer and more comfortably. Those with more severe cases of heart failure may benefit from surgery to repair damaged heart valves or unclog arteries.

Cardiology at Highland

To meet the rising demand for cardiology care, Highland has expanded its program with:

The Heart Failure Center at Highland Hospital: This new inpatient unit at Highland Hospital has a specialized team of providers including cardiologists, hospitalists, dedicated nursing staff, cardiac nurse practitioners, physician assistants, physical therapists, social workers and care managers. Patients receive evidence-based care in a skilled, closely monitored setting.

An expanded team of cardiologists: Highland's program now has five full-time cardiologists to provide open access to care. "If patients need to be seen the same

day or next day, we can and will *always* accommodate their needs," notes Dr. Teeters.

Advanced technology for faster diagnosis and treatment: Highland has invested in V-scans, handheld echocardiogram devices, so cardiologists can test patients at the bedside in the ED - or even while they are still in an ambulance - for a faster diagnosis and expedited care.

Highland cardiologists also use AliveCor Heart Monitor devices that attach to an iPhone and enable cardiologists to record a patient's electrocardiogram at a moment's notice.

Safer transitions from hospital to home: For heart failure inpatients, the first 72 hours after discharge is an important predictor of their long term outcomes. Highland's Heart Failure Follow-Up Clinic gives patients helpful education about their condition and a guaranteed follow-up outpatient visit with Highland Cardiology or their private physician within days of discharge.

"With our new multidisciplinary and technologically advanced approach to heart failure care, patients can receive the care they need in a smaller more comfortable setting such as Highland," Dr. Teeters notes. "We're very encouraged by the results and patient satisfaction we've achieved with our new inpatient unit and the Heart Failure Follow-Up Clinic."

Coping with Heart Disease: A Patient Checklist

A range of lifestyle changes can help individuals with heart failure or those at risk for the disease live long and productive lives.

- Reduce sodium intake. Aim to consume less than 1,500 to 2,300 mg of sodium a day.
- Restrict *fat* and cholesterol, which can raise your risk of developing coronary artery disease, a leading contributor to heart failure.
- Cut down on alcohol and fluids. Alcohol use can weaken the heart and may interact with some heart failure medications. Excessive fluid intake can worsen severe heart failure.
- Exercise regularly to help strengthen heart muscle. Quit smoking.
- Ease stress. The rapid heart rate and heavy breathing associated with stress cause your heart to work even harder.

For more information about Highland Cardiology, visit HighlandHospital.org. To make an appointment, call (585) 341-6780.

Could a Gluten-Free Diet Be Good For You?

Reprinted from: *Advancing Care – A Family Health Publication from Highland Hospital – Summer 2013*

By: Anil Sharma M.D

Just a few years ago, the term "gluten" was unfamiliar to most Americans. But today this protein found naturally in wheat, rye and barley has achieved some notoriety in mainstream culture. Gluten has long been known for its role in celiac disease - an autoimmune disorder in which the body attacks the lining of the small intestines when gluten is present, leading to troubles absorbing nutrients. It has more recently been blamed for a range of gastrointestinal symptoms in adults and children considered sensitive to gluten. Although there is no official data, some estimates indicate that as many as 17 million Americans - about one in 18 - may be gluten-sensitive.

"If you have celiac disease, you need to completely avoid gluten, which can cause intestinal damage. It's a lifelong change. But even some of my patients who don't have celiac disease find they feel better on a gluten-free diet - probably because when they cut out bread, pastries and cakes, they are eliminating other non-healthy substances. They feel better and may even lose a bit of weight," says Anil Sharma, M.D., a local gastroenterologist and Medical Director of the Highland Endoscopy Center.

If you don't have celiac disease but want to try a gluten-free diet, consider these tips:

Be mindful of balance. Any type of restrictive eating plan can hinder your ability to achieve a balanced diet. For example, many breads, cereals and pastas are fortified with B vitamins and iron, while some gluten-free varieties are not. Take care in choosing a variety of foods at

mealtimes, including lots of naturally gluten-free fruits and vegetables.

Read labels. Gluten-free does not necessarily mean good for you, so it's important to check labels to ensure foods are low in fat, sugar and sodium.

Shop wisely. Sticking to the perimeter of the grocery store may be the best way to avoid gluten. It's here where you'll find many naturally gluten-free - and nutrient-rich - foods, including fresh produce; fresh meat, poultry and seafood; and egg and dairy products.

"If you are at high risk of celiac disease - if a close family member has it, or you are experiencing symptoms - you should see your physician and get a definitive diagnosis. He or she can order a blood test that's relatively simple and highly accurate," Dr. Sharma advises.

These common foods naturally contain no gluten.

- Corn
- Buckwheat
- Flax
- Potato starch and flour
- Quinoa • Plain rice
- Soy (but not soy sauce)
- Fresh fruits and vegetables
- Fresh meat, poultry and seafood
- Eggs
- Unflavored milk
- Cream
- Most yogurts
- Butter
- Aged cheese, cream cheese and cottage cheese
- Honey
- Peanut butter

TAO Comfort Bags

TAO is now providing comfort bags for transplant recipients and candidates while they are in the hospital. They are loaded with hand sanitizer, playing cards, puzzle book, Kleenex, lip balm, emery board, a bookmark with inspirational quotes, notepad, pen and pencil. In the past TAO members delivered the bags at the holidays but the board voted to make it an ongoing project throughout the year in order to support many more of the membership. Norm Breen (heart recipient) and Vice President Debbie Yendrzkeski distributed comfort bags to eight heart candidates and they were well received.

Suggestions for bag content or contributions to this project are welcomed.

Pictured: Top Left: Debbie Yendrzkeski and James Summers
Top Right: Terry Zink
Bottom Left: Fred Knewstubb
Bottom Right: James Milano



Membership dues for 2014 are due.

Your dues help sustain your organization and provide you with an information packed newsletter every two months. If you attend meetings, it covers your meals, and the rental of our conference meeting facility. It underwrites the picnic and holiday party, covers insurance costs, website and phone line. What a bargain for \$20 a year!

You will see a reminder on the back of the newsletter and a membership form. Please fill it out completely, even if you are a renewal, we update the member list, email list and anniversary dates from these forms. You also may get an email reminder.

Thank you for sending your dues in a timely manner. You will receive a postcard as an acknowledgement of receipt of your dues.

Tops Never Stops

Tops cards help TAO raise money.

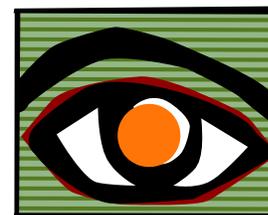
The Tops Gift Card Program allows our nonprofit organization to earn a 5% return by selling Tops Cards.

The more we sell, the more we earn.
The cards are available in \$25s, \$50s and \$100s.

Shopping at Amazon?

Don't forget, TAO can benefit from your purchases. Simply go to www.tao-rochester.org and click on the Amazon widget and do your shopping!

March is National Eye Donor Month



FACTS:

- you don't need perfect vision to be an eye/cornea donor
- you may still be able to be an eye/cornea donor after cataract surgery
- the 1st corneal transplant was performed in 1905
- about 60,000 people in the U.S. received cornea transplants last year
- the cornea is the eye's outermost layer. It is the clear, dome-shaped surface that covers the front of the eye

Those who suffer from corneal blindness due to disease, injury or infection may be helped by cornea transplantation. GIVE THE GIFT OF SIGHT



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TAO Members featured in video at 13th Annual Wine Auction to benefit URM C Cardiovascular Research

On November 9, 2013, Wegman's hosted its 13th Annual Wine auction.

Norm Breen, his wife Phyllis and daughter Clairissa were featured in the video which helped raise over \$1,000,000 for cardiovascular research at URM C Strong. You can watch the video at: <http://toasttoyourhealth.com/photos/>



Norm Breen with Dr. Clairissa Breen and Dr. Leway Chen, M.D., M.P.H. at the Wine Auction.

Don't forget to visit
and like our Facebook
Page



www.facebook.com/

Support Group Meetings

"OPEN AIRWAYS" - LUNG Gathering Group

Thursday, February 20 at 12 noon.
Winfield Grill - 647 Winton Rd. Rochester, NY
(Between East Main St and Browncroft Blvd.)
- and -

Thursday, March 20 at 12 noon.
Hicks & McCarthy - 23 S. Main St. Pittsford, NY

HEART Transplant/VAD Support Group

Thursday, February 13 at 6:30 p.m.
LVAD Specific Support Group -
*Must RSVP to Melissa Guerin LMSW at
(585) 273-2456 (Space is limited)*
- and -

Thursday, March 13 at 6:30 p.m.
Finger Lakes Donor Recovery Network

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

Join a Committee

Sunshine, Newsletter,
Membership, Awareness
Interested?

Call 1.888.664.1463

United Network for Organ Sharing

Candidates listed as of 1/31/2014

99,206	Kidney
15,725	Liver
3,748	Heart
2,043	Kidney/Pancreas
1,601	Lung
1,170	Pancreas
249	Intestine
45	Heart/Lung

121,164 TOTAL

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

www.unos.org

Save the Date . . .

April is Donate Life Month Mark Your Calendar

What you can do as a recipient—Write a letter to the Democrat and Chronicle's op-ed page. Tell your transplant story and emphasize the need to enroll in the NYS Donate Life Registry and the need for organ & tissue donation.

Wednesday, April 2 – Donate Life Awareness Night with the Rochester Amerks. For details, go to www.donorrecovery.org and click on Raising Awareness

Sunday April 6 - 12th Annual Rochester River 5K Run and Walk @ 10 a.m. hosted by Strong Memorial Hospital Transplant Programs and Friends of Strong. It will be held at the Roadhouse Shelter at Genesee Valley Park. There will be a ceremony honoring recipients at 9:30, all recipients are welcome. The event supports the patient care fund. Are you unable to attend but still want to support this event? Contributions can be made out to the Friends of Strong/River Run and sent to: Nancy Metzler, Transplant Administrator, University of Rochester Medical Center, 601 Elmwood Avenue, Box Surg/Txp, Rochester, NY 14642.

April 19 National Blue and Green Day

Spring showers in blue and green this April for National Donate Life Month! The month long annual observance honors those everyday heroes who say "yes" to organ, eye and tissue donation.

Support the power of donation by getting creative with blue and green.

Join us in drawing attention to the need for organ and tissue donors by wearing the blue and green colors of Donate Life for National Blue and Green Day on April 19. The initiative offers hope to the more than 117,500 Americans waiting for a life-saving transplant; honors the heroes of organ, eye and tissue donation; remembers those that died waiting for their second chance at life; and celebrates the recipients who received the gift of life through transplantation.



Flu Season is here!
Get Vaccinated!

TAO Holiday Recognition Dinner

The annual TAO Holiday Recognition Dinner was held Saturday January 11 at Joey B's in Fairport. Delicious food, a great view of the canal and wonderful people helped brighten a gray day! The TAO board recognized Geoff Foley, Norm Breen, Bonnie Haefner and Karen Guarino in appreciation of their many talents, time, and dedication to the organization. We couldn't do it without them!



Transplant Anniversaries

Gerald Bluff	Lung	February	2004
James Carlineo jr.	Liver	February	2006
Wayne Dickinson	Liver	February	1997
Louis Mascaro	Kidney	February	1979
Shirley Newman	Kidney	February	2008
Joseph Nolan	Kidney	February	2006
Aisha O'Mally	Heart	February	2004
Greg Post	Kidney	February	2008
Lana Way	Kidney	February	2008
Cynthia Boyer-Green	Kidney	March	1996
Rita Callaghan	Liver	March	2001
Jana Currie	Lungs (2)	March	2008
Karen Gledhill	Kidney	March	2008
Robert Hadsell	Liver	March	1997
Thomas Louer	Liver	March	2004
Paula Mckay	Kidney	March	1995
Jan Sharp	Kidney	March	2005
Lea Sobieraski	Liver	March	2013
Ralph M. Toscano Jr.	Cornea	March	1989
Dennis Wittman	Liver	March	2004

Welcome New Members

Arthur Lisi
Larry Mortellaro
Kathleen Hale-Boyles
Dinesha Sarver

Wishes of Wellness To

Phyllis Breen
Debbie Yendrzski

Transplant Times

Submission Deadline

For April / May 2014 issue:
March 3, 2014

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:

Ida & Michael Ferraulo in honor of Michael A. Ferraulo's 70th birthday

TAO received \$334 through ROC the Day contributions this year.

We thank all our ROC-stars who generously gave a financial gift. These contributions will be used for programming and materials that support transplant patients, candidates and their families throughout the year.

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

Board of Directors & Officers

President	Linda Barnard
Matt Felo	Chris Barry MD, Ph.D.
Vice President	Geoff Foley
Debbie Yendrzski	Karen Gledhill
Treasurer	Karen Guarino
Deana Dillon	Bonnie Haefner
Secretary	Amy James
Bev Shank	Janice Odenbach
Membership	Karen Porterfield
Norman Breen	



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Don't forget your 2014 Membership dues! Help support the TAO Mission



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.