



Transplant Times

Newsletter of Transplant Awareness Organization of Greater Rochester

2010 Donate Life Float "New Life Rises"

January / February 2010

www.tao-rochester.org

1.888.664.1463

Inside this issue:

Donate Life	
Rose Parade Float	1
GQ Contest Winner	3
Heart Healthy Tips	4
TAO Members	
Recognized	6
Save the Date	6
Transplant	
Anniversaries	6
Santa Spotted at	
Strong Hospital	7

TAO Meets

**3rd Wednesday
of the Month
at the
Al Sigi Center
Cafeteria**

**(Unless otherwise noted)
1000 Elmwood Ave.
Corner of South Ave. &
Elmwood Ave.
7:00 to 9:00 pm**

**ENTER DOOR 5
FOLLOW TAO SIGNS**

One donor lived only three days, but he saved the lives of two young girls, one of whom will ride in the 2009 Rose Parade in his honor. Another was 76 when he donated his tissue, demonstrating that age should not be a deterrent in the decision to donate.

The stories of the 76 people to be represented in "flora graphs" (artistic floral portraits) on the 2010 Donate Life Rose Parade float, *New Life Rises*, are equally dramatic and heart-wrenching, but they all share the same outcome: each was a donor of organs, tissue or corneas, and in 23 cases all three. More than 30 died before their 21st birthdays, yet they all made a profound difference in their young lives.

The floral images of this special group of organ, eye, and tissue donors will take center stage on the seventh Donate Life float entry in the 121st Rose Parade. The float features a phoenix, the mythical symbol of life coming out of the ashes of death and rising from a bed of flames 30 feet into the sky. The Donate Life phoenix represents those who give life in their passing and the people whose lives are renewed through transplantation. The flora-graphs will be integrated into the bird's tail feathers.

"The families of these donors have grieved the loss of their loved ones, yet they will celebrate their lives when the Donate Life float and its flora-graphs journey down Colorado Boulevard on New Year's Day," said Bryan Stewart, chairman of the Donate Life float committee and vice president of communications at OneLegacy, the



nonprofit organ and tissue recovery organization serving the greater Los Angeles area. "We know from past experience that the process of decorating the flora-graphs can be healing for the donors' family members, and we look forward to working with them as these beautiful portraits are decorated in December."

While some families will travel to Pasadena in December to decorate their loved ones' flora-graphs, as many as 30 portraits will be sent to families nationwide for completion in their hometowns. Most of the flora-graph decorating events will be
(continued on page 2)

Membership Meeting Guest Speakers / Topics

**January 16, 2010 (Saturday)
In lieu of January 20 Meeting
TAO Recognition Dinner**

(See details inside)

**February 17, 2010
Linda Maiellano**

Katie's Star Memorial Fund

(‘New Life Rises’ continued)

held at locations that were significant to the honoree’s life and donation, including elementary and high schools, churches, and hospitals. “Dozens of families will have the opportunity to decorate their portraits surrounded by loved ones and those in their community who were touched by the honorees’ donations,” Stewart noted. “We are grateful to the float’s floragraph sponsors for helping us create this meaningful opportunity for our honorees’ families.”

As 85 million Americans have already done, several of the honorees had enrolled in their respective state organ and tissue donor registries prior to death. More than 28,000 lives are saved each year in the U.S. through the gift of organ donation, giving hope to the more than 104,000 people awaiting a life-saving organ transplant. In addition, every year hundreds of thousands of people need donated corneas and tissue to prevent or cure blindness, heal burns or save limbs.

The 2010 Donate Life float will also carry 24 riders who have their own important stories to tell. In addition, donors across the country will be memorialized in a garden of hundreds of roses dedicated through the Donate Life Family Circle program, with each rose vial carrying a personal message of love, hope and remembrance.

Coordinated by Donate Life America member One Legacy, the national Donate Life float campaign is supported by approximately 60 official partners from coast to coast, including organ and tissue recovery organizations, tissue banks, state donor registries, transplant centers and affiliated organizations. Joining OneLegacy as top-level benefactors are Astellas Pharma US, Inc., a fourth-year sponsor of five float riders through the “Ride of a Lifetime” contest and supporter of 1,000 volunteer decorators; the American Association of Tissue Banks (AATB); the Dignity Memorial® network; Donate Life America; and UNOS and the National Donor Memorial. All float partners encourage parade viewers to save lives by registering in their states to be organ, eye and tissue donors and donating blood in their communities.



Edward J. Kraus, Astellas representative presented **Resources for Transplant Patients** at the November meeting.

An open letter to TAO from Astelles

Dear Transplant Awareness Organization:

You and your members may be aware that generic versions of multiple immunosuppressant medications, including Prograf® (tacrolimus capsules), are available at pharmacies across the country. It is critical that patients are educated on the importance of checking their medication *every time* they refill their prescriptions to make sure they are getting the exact medication intended for them. In many states, pharmacists are not required to alert patients or their doctors when a generic drug is substituted for the brand.

The National Patient Safety Foundation® (NPSF) recommends that patients double-check before leaving the pharmacy that they are taking “the right dose of the right drug, at the right time, in the correct way.”¹ When patients pick up their prescription at the pharmacy, they should always make sure that it matches what their doctor has prescribed¹.

Please inform your members about the importance of talking to their doctors about which immunosuppressant medication is right for them—and *remind them that they should not stop taking or change their medication on their own without their doctors’ advice*. Taking a medication other than what was intended for them may increase their risk for organ rejection or cause serious side effects.

Also, please keep in mind that Astellas Reimbursement Services has assistance programs that can help patients cover the cost of their Prograf prescriptions. One of these programs is the Prograf Value Card, which could save them up to \$100 on each of their next 12 Prograf prescriptions.* Patients can find out if they qualify by visiting www.transplantmedsavings.com.

To learn more about the programs offered by Astellas Reimbursement Services, please call 1-800-477-6472 or visit www.astellasreimbursement.com. If you have any questions, please contact me at kevin.fowler@us.astellas.com. Together, we can help patients take an active role in protecting their transplants by making sure they receive the medications their doctors want them to take.

Sincerely,

Kevin J. Fowler
Senior Product Manager
Patient Education and Advocacy Relations

*Subject to eligibility. Restrictions may apply.

Reference: I. Pharmacy safety and service—what you should expect: a consumer fact sheet. National Patient Safety Foundation Website.

<http://www.npsf.org/download/PharmacySafety.pdf>.
Published 2003. Accessed July 7, 2009.

Local Man Wins GQ Magazine "Better Man, Better World" Contest

John Piano, who grew up in Greece, won the votes and hearts of the GQ readers in GQ magazine's "Better Man, Better World". Readers were asked to nominate an agent of change striving for the betterment of society through charitable work, volunteerism, and/or community involvement — someone who is working hard to make this a better world. GQ then selected the five best submissions as finalists which they then put to a vote by GQ readers. John's efforts have touched many thousands of lives across the U.S. in just 6 short years. Through his resourcefulness, talents and dedication, John has significantly contributed to creating a better world.



**John Piano
President & CEO,
Transplant Connect**

John has dedicated the last 6 years of his life to help increase lives saved and improved through organ, tissue and eye (cornea) transplantation. He is not a surgeon or health care administrator or politician; rather, he's a creative entrepreneur who has built modernized electronic medical records software for the transplant field.

Back in 2003, John made an enormous sacrifice and life decision. John walked away from traditional successes as an Ivy League-educated corporate attorney, media executive and Internet entrepreneur. Driven by his passion to contribute to society in a more meaningful way, John created far-reaching partnerships with leading transplant surgeons and organ, tissue and eye transplant organizations spanning from California to New York and Washington, DC and many places in between. Working closely with these partners, he created a software organization Transplant Connect to replace the inefficient

paper/ phone-based communication of the traditional donor-transplant process with modern, real-time, Web-based software. His website, Transplant Connect, (<http://www.transplantconnect.com/>) reaches out to people across the country and here in the Rochester area.

John's work helps those who are working against daunting odds : more than 104,000 people in the U.S. alone are waiting for organ transplants. Approximately 18 of them will die every day due to the unavailability of organs. More than 10 million men, women and children worldwide suffer from corneal blindness that can be eliminated through corneal transplantation. Many others can be helped through the transplantation of bone, heart valves, skin and other tissues that is in short supply as well.

Constantly traveling and often working for no salary, John's dedication was so strong, he even mortgaged his Los Angeles beach house to fund his organization's efforts in the early days. His perseverance and commitment has remained unyielding through those challenging and difficult times.

Transplant Connect has directly expedited, improved and modernized transplantation. Today, nearly 50% of all U.S. organ transplants are enabled by the software John's organization created, and with his software, faster and better decisions are made, with the result that more lives are saved and improved.

Heartfelt thanks go to GQ for honoring a most deserving person.

Staples Rewards Program

If an individual makes a purchase at Staples and does not have a personal rewards program card, purchases may be credited to the Transplant Awareness Organization.

Just ask the clerk at the register to please apply reward credit to the TRANSPLANT AWARENESS ORGANIZATION

United Network for Organ Sharing

Candidates listed as of 12/4/2009

82,902	Kidney
15,803	Liver
2,962	Heart
2,215	Kidney/Pancreas
1,860	Lung
1,501	Pancreas
231	Intestine
83	Heart/Lung

105079

TOTAL

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

www.unos.org

Love Your Heart: Practical “Heart Healthy” tips for lowering fat in your diet and understanding “good” from “bad” fats.

Elizabeth Keirstead ,RD, CNSD
Transplant Nutritionist, URM

Do you know where fat can ooze into your diet?
Take the quiz below and see how your diet scores...

Question	Seldom or Never	1-2/week	3-5/ week	Almost Daily
How often do you eat / use the following:				
Fried, deep-fat fried or greasy breaded foods.				
Fatty meats; sausage, salami, bologna, heavily Marbled meats, skin/visible fats on meat, meat < 80% lean				
Whole milk, regular cheese or ice cream, high fat Cream cheese/sour creams, real cream.				
High fat desserts; pies, custards, pastries, rich cakes				
Breads with fat; croissants, high fat muffins or breads, chips, packaged cookies or snack cakes.				
Butter, margarine, oil added to vegetables, breads, rice, or pasta.				
Regular mayonnaise and salad dressings.				

Review your answers. If you have the majority marked in the far right two columns, this indicates that you may have a diet higher in fat than you thought. Use this knowledge as an opportunity to cut back on the amount and/or find lower-fat food choices.

Reducing fat in your diet to < 30% of your total calories per day

Benefit: Reduction in the caloric intake from fat can help you loose weight.

Fast Fat Facts:

Fat is a food group to reduce (but not eliminate).

Fat contains twice the energy compared to calories from carbohydrate and protein.

Your fat soluble vitamins (A, D, E, K) need fat to be absorbed by the body, but we require less than today’s society provides.

Calorie content:

1 gram of fat X 9 = 9 calories

1 gram of carbohydrate X 4 = 4 calories

1 gram of protein X 4 = 4 calories

Contrast and Compare:

Have you ever compared the calories in a carbohydrate or protein food that is high in fat to one that is lower, it will boggle your mind!!

Examples:

½ cup Cabbage/veggies with vinegar, sugar substitute or fat free salad dressing = ranges 50-70 calories V.

½ cup Cabbage/veggies with 3 teaspoons of regular fat dressing (same as 1 tablespoon) = 150-200 calories.

1 medium apple = 60-80 calories, depending on the size. V. Baked apple with sugar and cinnamon = 150-200 calories.

Devil’s food frosted cake = 405 calories V. Apple Pie = 455 calories V. Cheesecake = 460 calories V.

This table can give you a guideline for looking at products you buy and discovering what each meal adds up to in quantity and type of fat.

Calories	Person/activity	Tot. grams fat 30% of calories	Tot. grms sat fat 10% of calories
1600	Sedentary women, young children, elderly	53 grams fat	18 grams saturated fat
2200	Children, teenage girls, Active women, pregnancy, breastfeeding, sedentary men	73 grams fat	24 grams saturated fat
2800	Teenage boys who are active,very active men, some active women	93 grams fat	31 grams saturated fat

What about Cholesterol (another type of fat)?

Cholesterol is a type of Fat found in animal products only, because it is produced in the organ called the liver. So, your game plan is to find animal products that are lower in the grams of saturated fat and cholesterol. Another tip is to keep your diet varied and introduce plant source proteins to dilute out or substitute for the animal ones.

Meat Substitution Tips:

Reduce the quantity, make sure it is lean (90-95% lean), trimmed of any visible fat, then add some beans/legumes (chickpeas, beans, lentils);Or,

Completely substitute Bean/legumes meat

If you have never used plant proteins (tofu/soy, beans, legumes,nuts), it is not wise, sometimes, to go it alone. Look for trusted recipes that have already done the work for you

Cooking method: When using leaner meats, overcooking and high heat/low moisture cooking can make them into shoe leather!

The Fish Story

Fish is recommended 3-4 times per week or as much as you can fit into your schedule.

The meat of most fish is naturally low in fat, rich in polyunsaturated fat and omega 3 fatty acids. Omega 3 fatty acids appear to slow down the process of blood clotting, which can cause heart attacks and strokes.

Research has shown from populations who have a diet rich in fish to have lower rates of heart disease.

There are many ways to prepare fish. The more variety the better to balance higher fat to lower fat cooking, for example, poaching/steaming=lower fat to pan frying with small amount of oil=higher fat. Another great way to prepare fish; coat with ground nuts instead of bread crumbs and bake it, the oil from the nuts will flavor it nicely!

Other "Heart Healthy" Fats:

Not fond of fish, you say???? Canola oil and soybean oil also provide some omega 3 fatty acids - just keep an eye on the quantity you use.

Tips on types of fat:

Oils high in saturated fat:

These fats are hard on your health

Coconut oil	Any animal fat on meat
Palm Kernel oil	Palm oil
Butter	Animal lard
Cream	Crisco
Cocoa butter	

Oils high in unsaturated fat:

These fats are better for your health

Safflower oil	Sesame oil
Sunflower oil	Peanut oil
Corn oil	Canola oil
Soybean oil	Olive oil
Cottonseed oil	

In Summary:

- Choose low fat dairy products (Skim, nonfat or 1%).
- Choose lean meats (90-95% lean), poultry without skin and fish.
- Eat moderate portions of meat, poultry or fish, keeping total amount to 6 to 8 ounces per day, unless advised otherwise. (One pound of meat feeds 4 people.)
- Use low fat preparation methods to prepare foods (steam, bake, grill, poach, broil).
- Choose broiled, grilled or roasted entrees when eating out.
- Reduce amounts of fat added at the table and in cooking.
- Use liquid vegetable oils rather than solid fats (butter, margarine or lard) and shortening whenever possible.
- Eat high fat bakery or processed products less often, read your labels and compare to find products to fit into your heart healthy diet.

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 next issue. **THANK YOU.***

- David C. Spiro
- Louis J. Mascaro
- Mike Swete
- Shirley Tuites — In memory of Dick Tuites
- Helen and David Cox
- Mary L. Stein
- John F. Schroth, Jr — In Memory of Chester Palozzi

- In Kind:**
- Karen Gledhill
 - Kathleen McCaffery
 - Mary L. Stein

Save The Date . . .

Saturday January 16

TAO's Holiday Recognition Dinner

Green Lantern Inn, Victorian Room
1 Church Street, Fairport, NY.

Appetizers will be served at 5PM followed by a buffet dinner.

Cost is \$10 per person. TAO will be partially underwriting the cost of dinner.

Reservations are needed and can be made by sending a check made out to TAO, PO Box 23552, Rochester, NY, 14692-3552, no later than January 8, 2010.

Any questions please contact Debbie at 377-6028 or by email at auggieday@aol.com, subject: party. We hope to see you there!



Saturday, February 27

BEAT THE WINTER BLAHS FUNDRAISER FOR TAO

Join us for a day trip to **The Seneca Niagara Casino**.

All invited – TAO members and non-members. A minimum of 40 people is required.

Cost is \$35 per person of which you will receive \$20 for slot coins, a \$5 food voucher and bus ride to and from the casino.

The bus will depart from the Bushnell's Basin Park & Ride on Rt. 96 at 9AM and depart casino at 4:30 PM to arrive at Bushnell's Basin at 6PM.

For more information and reservations, contact Debbie by phone, 377-6028 or by email auggieday@aol.com, Subject: *Casino trip*.



Sunday, February 21

National Kidney Foundation's, Upstate New York Transplant Team Bowling Fundraiser.

The event will be held at Parkview Lanes, on Culver Road near the entrance to Durand Eastman Park. Squad times are being determined. If you would like to know more information, please call Karen Gledhill at 586-9252.

Our Condolences ...

Our deepest sympathies go out to Norm and Phyllis Breen on the passing of Norm's sister and to Kathleen McCaffery on the passing of her sister. Also to the family of Ted Rozestraten and to Barb Lyman and family on the passing of Ray Lyman.

If you are aware of members that we should list in *Wishes of Wellness*, or to express our condolences to, please call TAO and leave a message at 1-888-664-1463.

Fund Created in Memory of Katie Lynn Maiellano

Katie Lynn Maiellano was a 22-year old from Pavilion, NY, who was fatally injured in an automobile accident on August 15, 2006. At the time of Katie's death, her family donated her organs and tissues, as was her wish. Several people benefited from her gifts.

After Katie's death, family and friends started the Katie's Star Memorial Fund of REHPB as a way to keep her spirit alive.

The Fund's purpose is to assist organ donors, recipients and their families with their travel and lodging expenses when they come to Western New York for a transplant. The Fund also will inform and educate the general public on the need for organ, eye and tissue donors. To date the Fund has allocated \$400.

For more information about the Fund, how to make a contribution or inquire about receiving funds, please call (585)272-7890 or 1-800-568-4321, or email Karen Guarino at kguarino@rehpb.org.

TAO Members Recognized

Bonnie Haefner, TAO Board member received the Glazer Distinguished Volunteer Service Award. This award is presented to an outstanding volunteer committed to fulfilling the mission of the National Kidney Foundation. It is named after one of the NKF's local founders, Larry Glazer. Congratulations Bonnie!

Tim Parks was presented with the DiPasquale Spirit Award for being an outstanding individual who faces the challenge of kidney disease head on, and in doing so, encourages others to do the same.

Transplant Anniversaries

Elizabeth Brian	Liver	January 2005
Helen Cox	Kidney/Pancreas	January 1996
Dan Diulio	Liver	January 2003
Frank Imburgia	Heart	January 2003
Chuck Liberi	Kidney	January 1995
Ann Marie Scroger	Liver	January 2007
Pat Stewart	Kidney	January 1994
Guy Valone	Kidney	January 2009
Jerry Bluff	Lung	February 2004
Matthew Felo	Lung	February 2007
Patricia Legge	Kidney	February 1996
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
Scott Sanford	Liver	February 2009

Thank You card from Joe Haefner:

"Thanks for all the prayers & support. The blanket I received in the hospital was a very "warm" gesture. It's still keeping me warm at home. Thanks again."

POP TABS: The Alpha Phi Omega Fraternity at SUNY Geneseo is aiding us in our effort to help a gentleman attain his goal of saving "a ton of tabs" for the Harbor House. If you have any tabs bring them to the meetings or call Linda Barnard at 585-227-2887 to make arrangements for her to collect them. Thank you in advance.

(L to R) Alpha Phi Omega Representatives and Linda Barnard



Board of Directors & Officers

President

Jerry Runion
jgruion@rochester.rr.com
(585) 733-3422

Vice President

Sandy McNitt
sdmcnittot@aol.com
(585) 359-8015

Treasurer

Dave Johnson

Secretary

Sally Stelljes

Linda Barnard
Karen Guarino
Jim Fyfe
Bonnie Haefner
Linda Hicks
Rob Kochik
Katherine Norway
Janice Odenbach
Bev Shank
Mike Stelljes
Sally Stelljes
Dennis Stenshorn
Debbie Yendrzeski

Transplant Times

Submission Deadline

**For March / April issue:
Monday, February 8, 2010**

**Articles /ideas email to:
auggieday@aol.com or
kbliek333@gmail.com
or send by mail to:
TAO, PO Box 23552, Rochester, NY 14692-3552**

Santa Spotted at Strong Memorial Hospital

Santa arrived at Strong Memorial Hospital on December 9, accompanied by a few of his "elves" and was seen spreading good cheer and delivering fruit and snack baskets to staff and gift bags to patients on 6-1600 and 7-3400. "The bags were filled with items such as note pads, word search puzzles, chap sticks, and seasonal items," stated Debbie Yendrzeski, elf and TAO member.

Debbie, along with other TAO members (aka:elves) Bonnie Haefner, kidney recipient; Ben Smeenk, kidney recipient; Mike Yendrzeski, liver recipient; and Kathleen McCaffery, kidney transplant candidate; helped Santa (aka: Jim Fyfe, heart recipient) deliver holiday bags to a total of forty-seven patients.

The wife of a recent heart recipient said, "You nailed it with the gifts," thanking TAO for bringing a bit of cheer to all. "This is the second year that TAO has sponsored the holiday gift baskets and bags," said Haefner. "It's TAO's mission to give support to those who have had transplants, those waiting and those who care for them."

The morning was filled with smiling faces from staff, patients and visitors alike who were greeted by Santa's merry Ho-Ho-Ho.

*From left to right:
Kathleen McCaffery, Bonnie Haefner, Debbie Yendrzeski and Benjamin Smeenk*



Sharon Litto, NP and Santa (Jim Fyfe)



Kate Norway, RN and Mike Yendrzeski





Return service requested

PO Box 23552
Rochester, NY
14692-3552

If you receive more than one copy,
or you would like to be removed
from our mailing list, please send an
e-mail to:

Subscriptions@tao-rochester.org

Or a written request to:

TAO

PO Box 23552
Rochester, NY
14692-3552



TAO / Rochester Membership Application

No one is denied membership because of financial considerations

- Checkboxes for New Member, Renewal, \$10 Family, \$10 Institutional, and unable to make dues payment at this time. Includes a Date field.

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

- Checkboxes for Candidate, Recipient, Family Member, Donor Family, Friend, Professional

Candidate/Recipient information: # of Transplants Hospital

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