



# Transplant Times

Newsletter of the Transplant Awareness Organization of Greater Rochester

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

November / December 2012

www.tao-rochester.org

1.888.664.1463

### Inside this issue:

- Looking for ways to be Part of TAO? ..... 2
- RETB Celebrates 60 Years of Service ..... 3
- The Relationship Between Diet and Blood Pressure ... 4
- Transplant Fundraising Tips ..... 6
- Save the Date ..... 7

## A Message from the President



Hi, my name is Matt Felo and I have been appointed president of TAO. I hope that I can do as good a job as Geoff has done over the past years. He has brought much to the TAO organization and has left big shoes to fill. His dedication to the organization and the people we support has been a model of what and who we are.

I received a single lung transplant over five years ago at the Cleveland Clinic. I have been a member of TAO for about four years, I volunteer with Friends of Strong's pre and post-transplant groups, and with Rochester Eye & Tissue Bank and Finger Lakes Donor Recovery Network as well as being a board member for the past two years.

I have been married to my wonderful wife Sandy for forty-five years. She is a Registered Nurse at Highland Hospital and if it wasn't for her I would not be here today. Her support and the support of my daughters has been the backbone of my recovery. We have two married daughters, three terrific grandchildren, and two great sons-in-law.

One of the goals I would like to set is to increase our membership by 10% each year and to make people more aware of organ donation in the community. I welcome help from anyone who is willing to help TAO grow and be more recognized in the community.

I look around and see many people who have dedicated themselves to our organization and wish we had four times as many to share the load. I have been approached by many of you with suggestions and with your concerns. I am open to any suggestions on how to

increase participation at meetings and other events.

We have a several upcoming events for fundraising; our meeting on November 19 will be held at Simply Crepes and they will donate a portion of the cost of your meal to TAO. If you have breakfast or lunch there that day, mention that you are there because of the TAO fundraiser and a portion of your meal will go to TAO. We will also have a Tupperware sale in November, holiday gift wrapping at Barnes and Noble in December, a Delta Sonic Car Wash Sale, and last but not least, the annual Roc the Day on December 12. You can designate either all or part of your United Way contribution to TAO just by designating Tao # 2493 on your form in the appropriate spot. Your friends, family and neighbors are welcomed to join in the events scheduled over the next two months. After the first of the year we will have our annual Holiday party and our second annual Euchre Tournament.

I hope to see a lot of new faces at these events and at our monthly meetings. Without your support we won't be able to grow. Again thanks to all who volunteer and support our organization and for the support of the board members.

*Matt Felo*

### Membership Meeting Guest Speakers / Topics

**November 19**  
*Dining at Simple Crepes*  
*Schoen Place, Pittsford*

**December**  
*No Meeting -*  
*Happy Holidays!*

### TAO Meets

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

## Looking for a way to be part of TAO?

**Tupperware makes a nice gift!** Place an order and have it in time for the holidays! All orders need to be in by November 16th. Cash or checks ONLY. Checks can be made out to Jen Stracke. Send your order to Matt Felo, 40 Captiva Crossing, Fairport, NY 14450 with the payment. December 3 is the anticipated arrival date.

Orders can be picked up at Matt's house on Thursday Dec. 6 anytime that day. If unable to pick up your order that day please call Matt at 585-749-6287 to make other arrangements for delivery. Please be sure to include a phone number on the order blank. Thank you!

### ROC the Day- December 12, 2012

This is a one time this year donation, separate from your annual pledge to United Way. We ask that you spread the word to your friends and family, asking them to think of TAO during this season of giving and designate # 2493 (TAO)

**Delta Sonic Car Washes** Keep your car clean this winter! Two car washes for \$5 are available (with a value of \$5 each) and will be sent to you the second week of December. They will keep their \$5 value for 60 days after that, i.e. until about February 10th (and have a value of \$2 for another 60 days after that). Please email Geoff Foley at GeoffF21@yahoo.com or call him at 585-383-1559, with the number of cards required, your name and address. Checks should be made out to "TAO" with "Delta Sonic" on the memo line and mail to TAO, P.O. Box 23552, Rochester, NY 14692-3552. These make great stocking stuffers!

**Amazon** Do your shopping on Amazon by first going to the TAO website, tao-rochester.org and click on the Amazon widget and place your order. TAO benefits from your orders!

**Tops Cards** are available in \$25, \$50, and \$100 increments. If you shop at Tops or are looking for a gift, purchase prepaid gift cards from TAO. Contact Bonnie at (585) 391-3555.

**TAO Membership dues . . .**  
are now due for the upcoming year.  
Your membership dues are used for  
funding support initiatives and social  
activities of TAO.

## Transplant Unit at Strong has Moved.

The Transplant Unit is now located on 4-3400.

Currently the 4<sup>th</sup> floor houses the Golisano Children's Hospital. Once the new addition to the hospital is built, renovation of the 4<sup>th</sup> floor will take place that will include a change in decor, from child-friendly to adult. There is a visitor's lounge with a more "home" atmosphere where family members can visit with patients for a change of scenery. Future plans include an outdoor patio off the lounge.

Stop in if you find yourself at a clinic appointment and check out the new unit and say hello to all the familiar faces!



## TAO Fundraiser at Hank's Ice Cream a Sweet Success

Thank you to all that came out and enjoyed the beautiful late summer evening at Hank's in Webster, NY. An added bonus was the music from the Duke of Earl and a vintage car cruise night. Not only did this result in raising needed funds for TAO, but also raised awareness of the organization. The funds raised for TAO will help TAO continue programs and projects for transplant recipients, candidates and their families.

A big thank you to the staff at Hank's for their kindness.



Matt Felo (L) and Debbie Yendrzeski present a Certificate of Appreciation to Chris Frank at Hank's.



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

## Rochester Eye & Tissue Bank Celebrates 60 Years of Service

The Rochester Eye & Tissue Bank (RETB) hosted a 60th anniversary celebration luncheon on Saturday, September 21, at Mario's Restaurant. RETB Administrative Director Loel Turpin welcomed more than 100 guests who attended the luncheon, thanking them for their roles in helping the agency continue its work and for the support received by many in the audience. Rebecca Leclair emceed the program which included keynote speaker RETB Medical Director Steven S.T.Ching, MD, who has held this position since 1985. Those attending heard from 17-year-old Lindsay Rohrbaugh's mother, Holliday, how her daughter's corneal transplants have given Lindsay the opportunity to pursue her dream of becoming an illustrator and RETB's own Tissue Bank Coordinator Andrew Pakan spoke of receiving donor tissue for two ACL surgeries that helped him continue playing football at college and how working for the agency provides him an opportunity to help others. The agency was established in 1952 by the Downtown Lions Club with support from other area Lions Clubs. It began solely as an eye bank and in the mid 1980s began recovering other tissue due to community need in advancing medical technologies. To date, the agency has provided more than 11,000 corneas for transplant surgeries and other tissues such as heart valves, bone, skin, tendons, ligaments that have helped hundreds of thousands of individuals in the community and beyond. Its grant program has awarded more than \$1,000,000 to local researchers for ocular and transplant-related research projects. RETB is a nonprofit 501 (c) 3 organization and is an accredited member of the Eye Bank Association of America and serves the Finger Lakes, Central, Northern, Southern Tier NY regions as well as North Central PA. The administrative office and laboratory are located at 524 White Spruce Blvd. Rochester, NY.

## 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

## Volunteers Needed

Volunteers are needed to share their personal transplant story for school presentations and to staff Health Fairs and other events for RETB and FLDRN. We also have many clerical opportunities. If you are a new volunteer, who has completed the volunteer orientation program and needs to "shadow" a staff member at an event, please contact Pat Moorehouse at 585-272-7890 so we can schedule that valuable hands-on experience. It is because of you, our volunteers, that we are able to increase enrollment in the NYS Registry and continually educate the community about the benefits of organ, eye and tissue donation. Thank you for all you do!

## It was a Beautiful day for a Walk in Seneca Park.

The Kidney Cares 2012 Second Annual Walk was a great success. Thank you so much for walking with us. More than 250 people spent a wonderful autumn morning connecting and sharing their precious time for a great cause. Their participation will help us continue to grow and provide patient services to our kidney community. We're still receiving donations! So if you would like to make a gift to Kidney Cares, the lines are open! Congratulations to all of our raffle winners. We hope you enjoy the prizes. Thank you to all of our sponsors. Your generosity is a true example of supporting the local community. We hope to see you again next year. A very special thank you to all of the volunteers who made the day a success. Kidney Cares could not exist without your tireless commitment to our fledgling organization. Your work is deeply appreciated. We're already planning our next events and strategies for the future. Please be sure to stay in touch and let your friends know about Kidney Cares. We're just getting started. Together we will make a difference. Thanks again.

Be sure to subscribe to our E-newsletter to receive announcements and keep up-to-date on the latest developments from Kidney Cares.

For more information call 585-467-4627 or email [kidneycares@gmail.com](mailto:kidneycares@gmail.com) or go to our website [www.kidneycares.org](http://www.kidneycares.org)

From all of us at Kidney Cares, thank you for your support.

## Transplant Times

### Submission Deadline

**For January/February 2013 issue:  
December 3, 2012**

**Articles /ideas email to:  
[aggieday@aol.com](mailto:aggieday@aol.com) or send by mail to:  
TAO, PO Box 23552, Rochester, NY 14692-3552**

## The Relation Between Your Diet & Your Blood Pressure

By: Amy Readle, Dietetic Intern;  
Cornell Dietetic Internship

The 2010 Dietary Guidelines for Americans reported the most recent national survey data (1999-2004), which revealed that 1 in every 3 Americans has hypertension, defined as systolic blood pressure  $\geq 140$  mmHg and/or diastolic blood pressure  $\geq 90$  mmHg (1). Survey data revealed another 33% of Americans who are pre-hypertensive, defined as systolic blood pressure 120-129 mmHg and/or diastolic blood pressure 80-89 mmHg (1). With hypertension affecting so many individuals, nutrition and medical professionals are often asked, "What can I do to lower my blood pressure?"

Sodium is generally the first nutrient to come to mind; one common strategy for lowering blood pressure is to limit salt, or sodium, in the diet. While sodium intake is certainly important, most people forget about potassium, which also plays an important role in managing blood pressure; this is because sodium and potassium work together to maintain the correct balance of fluid within the body's cells.

### Quick Facts About Potassium:

- Studies show that increased consumption of potassium can lower blood pressure by lessening the adverse effects of sodium (1)
- Institute of Medicine (IOM) guidelines set the adequate intake level for potassium for adults at 4,700 mg/day (1)
- Average potassium intake among adults  $\geq 20$  years is only 2400-2800 mg/day (1)
- A low-potassium diet can contribute to high blood pressure (2)

- Foods high in potassium include fruits & vegetables such as white & sweet potatoes, tomato products (paste, juice, puree), bananas, spinach, and some juices (prune, carrot, orange) (1)
- High potassium protein sources include: beans, yogurt, milk, fish, and pork loin (1)

### Quick Facts About Sodium:

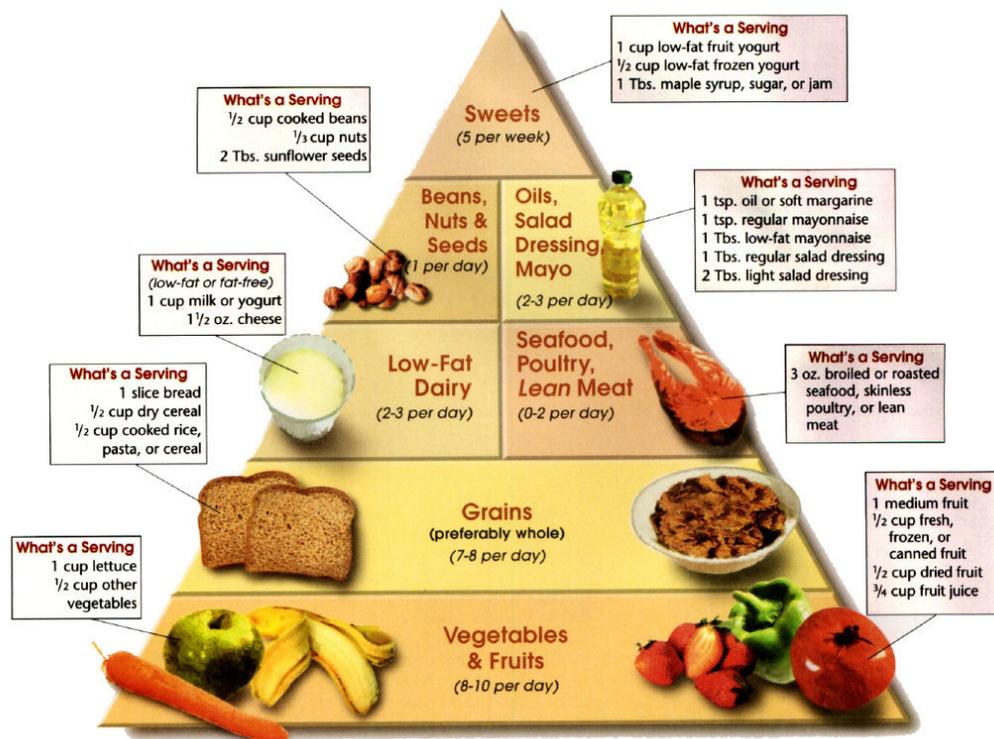
- Cutting back on salt in the diet can reduce blood pressure by 2-8 mmHg (1)
- IOM guidelines for sodium recommend the general population gradually reduce their intake to  $\leq 1500$  mg/day (1); average sodium intake is 3436 mg/day (1)
- 80% of Americans' dietary sodium intake is the result of food processing (2), with the top 5 contributors being yeast breads, chicken & chicken mixed dishes, pizza, pasta, and deli meats (1)
- The most common and effective suggestions for reducing one's sodium intake are to avoid cooking with salt or adding salt at the table and to read labels on prepared/processed foods
- Studies have shown that reducing sodium intake for as little as 3 to 4 weeks can decrease one's preference for salty foods (1)

### The Dietary Approaches to Stop Hypertension (DASH) Diet

As a transplant recipient the DASH diet works well; as it focuses on heart healthy, blood sugar friendly, high phosphorus and high magnesium food sources.

- The DASH diet (see pyramid below) evolved from a study that tested the effects of dietary patterns on blood pressure rather than individual nutrients (3)
- The original DASH diet study, which did not lower sodium intake ( $\sim 3$  g/d), was still effective in lowering blood pressure (3)

(continued on page 5)



Note: Choose lower-salt foods from all categories.

(continued from page 4)

The results of the DASH study revealed...

- ⇒ Among people with hypertension, the DASH diet reduced systolic blood pressure by an average of 11.4 mmHg and diastolic blood pressure by an average of 5.5 mmHg (3)
- ⇒ Even among those without hypertension, the results were still impressive with an average reduction of 3.5 mmHg in systolic blood pressure and an average reduction of 5.5 mmHg in diastolic blood pressure (3)
- ⇒ Reductions in blood pressure were achieved in just 2 weeks and were similar among all participants regardless of gender, age, and ethnicity (3).

**Adopting a healthy dietary pattern such as the DASH diet could delay or even prevent the need for blood pressure medications. Use the pyramid below for a quick guide to the DASH diet!**

**For more information on the DASH diet, please visit <http://dashdiet.org/> or contact Elizabeth Keirstead, RD, CNSD @**

**Elizabeth\_Keirstead@URMC.Rochester.edu**

#### References:

- 1). *US Department of Agriculture*. Report of the dietary guidelines advisory committee on the dietary guidelines for Americans, 2010. Part D. Section 6: sodium, potassium, and water. Available at <http://www.cnpp.usda.gov/dgas2010-dgacreport.htm>. Accessed March 30, 2012.
- 2). *Adroque HJ & Madias NE*. Sodium and potassium in the pathogenesis of hypertension. *The New England Journal of Medicine*. 2007;356:1966-78.
- 3). *Appel et al*. A clinical trial of the effects of dietary patterns on blood pressure. *The New England Journal of Medicine*. 1997;336:1117-1124.

## Our Sympathies To...

We extend our sympathies to the Dan Newhouse family and Jim Hey's family.

### Board of Directors & Officers

#### President

Matt Felo

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Geoff Foley

Karen Gledhill

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Bonnie Haefner

Amy James

Janice Odenbach

Karen Porterfield

## Transplant Anniversaries

Donna Crosby	Liver	November 2003
Peter Davis	Liver	November 1996
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
Larry Buck	Kidney	December 2000
Richard Forbes	Liver	December 2007
Richard Greene	Liver	December 2000
Mark Hackett Jr.	Liver	December 2010
Bonnie Haefner	Kidney	December 2005
Rick Juszkiewicz	Kidney	December 1996
Ruth Maines	Liver	December 1990
Stephen Odai	Liver	December 2001

### United Way Reminder:

TAO is recognized as a "donor designation eligible agency for the United Way campaign" Our agency number is 2493.



United Way  
of Greater Rochester

### United Network for Organ Sharing

Candidates listed as of 10/15/2012

93,946	Kidney
16,029	Liver
3,334	Heart
2,139	Kidney/Pancreas
1,630	Lung
1,233	Pancreas
260	Intestine
51	Heart/Lung

116,064 TOTAL

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

[www.unos.org](http://www.unos.org)

# Transplant Fundraising Tips

by Rick Lofgren, CFRE, President  
Children's Organ Transplant Association (COTA)

Many transplant families assume that a transplant is "private" and think they must travel the long road before and after a transplant by themselves. Nothing is further from the truth.

There are many ways friends and family members can help. One way is by organizing a fundraising campaign to assist with transplant-related expenses. At first, it may feel awkward to ask for help, but remember that family members and friends want to be involved in the transplant journey; take advantage of their willingness and genuine interest in helping your family. Here are some transplant fundraising tips:

## How to Begin Fundraising

1. Think about your resources -- groups and individuals who would likely help with a fundraising campaign. Start a list of those people including contact information.
2. Choose two or three key people who have the skills to take a leadership role in the fundraising effort.
3. Speak to those key people to determine their interest and ability to commit.
4. Talk to your family, friends and neighbors about your transplant-related financial need. Ask if they would join an effort.
5. Research organizations that can help you organize and train your volunteer group, and will assist with the financial aspects of the fundraising campaign.
6. Be prepared to step away from the fundraising efforts as your volunteers begin the campaign. Allow your volunteers to lead the campaign.

## Key Skills for Fundraising Volunteers

1. *Interest.*  
Key volunteers will be most motivated by the patient and his/her needs. Make sure key volunteers have a keen interest in the transplant patient.
2. *Organized.*  
Key volunteers must be organized. They will be tracking activities, volunteers, donations and plans. Do not ask someone who is disorganized to take a leadership role.
3. *Connected to the Community.*  
Key volunteers must have good community connections. They should have business, volunteer, membership, school and/or church relationships that they can call upon to help the fundraising effort.
4. *Communication Skills.*  
Key volunteers must be good communicators. The ability to speak to groups of people and to write effective letters, emails and copy for fundraising materials is critical. Key volunteers need to be able to get the job done.

5. *Flexible.*  
Key volunteers must be willing to shift gears when plans change. It is impossible to map out the entire fundraising campaign at the outset of the effort. Volunteers must be able to look at available resources and make plans accordingly.
6. *Committed.*  
Key volunteers must be committed to helping the transplant family. They must be aware of why fundraising is required. They should be willing to make a substantial time commitment to the campaign for at least a few months (or more).

Several national organizations exist to help organize and coordinate a fundraising effort for transplant-related expenses. Do not try to organize on your own because there are serious financial implications regarding using funds raised by a community. Before deciding to fundraise, please research these implications.

One option for transplant fundraising is the Children's Organ Transplant Association (COTA). COTA is a national charity that provides fundraising assistance to transplant families. Since 1986, COTA has been giving hope and making miracles for transplant families by working with volunteers from the family's hometown to raise funds for transplant-related expenses. 100% of all funds raised in honor of transplant patients are used for transplant-related expenses. For the past 26 years, COTA has worked with more than 1,900 transplant families and has helped to raise more than \$65 million for transplant-related expenses. During this time, more than 1,300 COTA patients have been successfully transplanted.

COTA works only with patients who need or have had a life-saving transplant who begin work with COTA before the age of 22 (although transplant patients who need a transplant due to a single cell genetic disorder like Cystic Fibrosis can work with COTA at any age). If you would like more information, please visit [www.cota.org](http://www.cota.org) or call 800.366.2682.

*Rick Lofgren, a Rochester (NY) native, was named President of the Children's Organ Transplant Association (COTA) in August 1998. During the past 14 years, he has worked to build the charity into a highly respected national fundraising entity that is singularly focused on saving lives. In addition to providing hands-on fundraising assistance to numerous volunteers nationwide, COTA has distributed more than 2,000,000 organ donor registration cards under Lofgren's leadership.*

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## Save The Date . . .

### Simply Crepes – All day Monday November 19.

Come have a meal and/ or dessert. Tell your server that you are there to support TAO and Simply Crepes will donate 10% of your check to TAO! In lieu of our monthly meeting, come and join us at 6 PM for dinner and socialization at Simply Crepes, 7 Schoen Place, Pittsford, NY. This is open to members, friends, neighbors and family. Let's prepare for the busy holiday season by giving thanks and sharing a meal together. We are trying to balance meetings and socials this year, giving people a chance to get to know one another, meet new people, and have some fun!

### Gift Wrapping - Saturday, December 15 9:00 am to 4:00 pm.

We need volunteers to staff 2 hour shifts, 2 people a shift to wrap purchases, bring awareness and maybe gain some donations. Please contact Bev Shank at 585-244-1536 or email shankbev@hotmail.com

**TAO Holiday Party Saturday, January 19** at the Brook House W. Ridge Rd. Meet at Noon, dinner at 1 PM. Details to follow in next newsletter.

## TAO Organ Specific Support Groups

### "OPEN AIRWAYS" - Lung Gathering Group

- Tuesday, November 6, at 12 Noon
  - Tuesday, December 11, at 12 Noon
- Location TBD (Mike's Diner is undergoing renovation and is closed until?) check the website and watch your emails for notification.

Contact Geoff Foley at 585-383-1559 or geoff21@yahoo.com if interested in attending.

### HEART TRANSPLANT/VAD SUPPORT GROUP

- Thursday, November 8, at 6:30 p.m. Strong Memorial Hospital 7th Floor Conference Room. Guest Speaker: Leway Chen M.D. M.P.H.
- Thursday, December 13, at 6:30 p.m. Annual Christmas Party Strong Memorial Hospital 2nd Level ACF-A&B (above the main lobby).

## Contributions

Janice Odenbach in honor of Dan Newhouse

## TAO Meetings



TAO President, Matt Felo (L) presents a Certificate of Appreciation to Dr. Eugene Storozynsky at the September TAO meeting.

Dr. Storozynsky gave a presentation on the Artificial Heart Program at Strong Memorial Hospital.



Matt Felo with Steven Goldstein President and CEO of Strong Memorial Hospital and Highland Hospital at the October TAO meeting.

Mr. Goldstein's presentation was on the latest update to Health Care Reform.

### Join a Committee

Sunshine , Newsletter,  
Membership, Awareness  
Interested?

Call **1.888.664.1463**



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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

- 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)