

Alliance for Paired Donation™ Newsletter

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Serving Kidney Patients Through Technology, Education and Generosity

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The Gift That Keeps on Giving: The Second NEAD™ Chain

In 2007, the Alliance for Paired Donation completed eleven successful kidney transplants using the paired exchange matching system. Continuing a series of events that began in July of 2007, the Alliance successfully pioneered the first Never-Ending Altruistic Donor (NEAD)™ chain. In the traditional method of paired exchange, the kidney patients who have a willing, but incompatible donor, are matched with others in a similar situation. The Alliance uses altruistic (or "good Samaritan") donors to begin a chain of transplants that can be performed in a step-wise fashion, rather than the surgeries being done simultaneously.

On December 7, 2007, the second chain of transplants was begun following a decision by Tracy Armstrong of Toledo, Ohio, to offer his kidney to a

stranger. In order to carry out the chain of transplants, Armstrong traveled to Columbus to donate his kidney to Debra, a recipient at Ohio State University Medical Center. Debra's daughter, Melissa, flew to Orlando, Florida to donate her kidney to Shirley at Florida Hospital Transplant Center. Shirley's daughter, Ethel, then flew from Orlando to the University of Toledo Medical Center to donate to Ronnie. However, a last minute positive cross-match (a blood test to make sure the donor and recipient are compatible) showed that Ronnie could not receive Ethel's kidney.

Dr Michael Rees studied the last few month's of data on the incompatible pairs in the APD system. "I realized we had already performed a successful cross-match test with Ethel and another recipient.

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Notes from the CEO

I am pleased to announce that Laurie Reece of Austin, Texas, has accepted the position of Executive Director of the Alliance for Paired Donation, Inc. Laurie has been employed by the Texas Medical Association, the largest medical association in the U.S., for the past 15 years, and for 12 of those years, she served as Executive Director of the Texas Transplantation Society. In this

capacity, she worked with the 27 transplant centers in Texas to promote and facilitate organ donation and transplantation, primarily through educational efforts and legislative advocacy.

Laurie was instrumental in helping form the Southwest Alliance for Paired Donation, which includes 21 centers in Texas,

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Our mission is to save lives by significantly reducing the wait time for a kidney transplant through kidney paired donation.



On the web at
www.theNEAD.com

Learn about kidney disease prevention and control

National Kidney Disease Education Program
www.nkdep.nih.gov

Frequently Asked Questions

Q. If my donor and I participate in a paired exchange, how does it work? Are the kidneys shipped to the other transplant center, or does my donor have to travel?

A. The APD strongly encourages all donors to travel to the transplant center at which they are donating. In our first year, we have not had any transplants for which kidneys were shipped. However, if both the donor and recipient centers feel that it is preferable to ship the kidney rather than have the donor travel, the APD allows the centers to make that determination for the patients under their care. While we believe that the donor traveling is the best option, the APD also supports the decision-making of the participating transplant programs.

Q. Who pays for the travel expenses?

A. For donor travel, we first determine if the donor is financially able to travel,

and if so, they pay for their own travel expenses. If they would have a hard time paying for some or all of the expense, we would then contact the recipient with whom they are matched to see if they can assist financially.

If the recipient cannot help with expenses, the recipient's transplant center would apply to the National Living Donor Assistance Center (NLDAC) for assistance.

(For more information, visit www.livingdonorassistance.org)

We may also refer donors to the National Transplant Assistance Fund (NTAF). For more information www.transplantfund.org.

And finally, if that does not yield enough assistance, and the donor meets the eligibility requirement, the APD may assist with travel expenses if funds are available. The APD has paid about \$10,000 in its first year to assist donors with their travel.

If you have a question related to Paired Donation, please email admin@paireddonation.org.

Notes from the CEO cont'd from page 1

Oklahoma, and Arkansas that are part of the APD, so she already is acquainted with many of you.

Laurie is working now to help all of our Alliance partners become active participants in the paired donation program.

You may contact Laurie at 512-961-6199 or by e-mail at Laurie.Reece@paireddonation.org.

World Kidney Day

March 13, 2008

- **13% of U.S. adults were estimated to have chronic kidney disease in 2000. Most were not aware of their condition.**
- **In 2005, 100,000 persons began treatment for end-stage renal disease in the U.S.**
- **By 2020 nearly 800,000 persons will be living on chronic dialysis or with a kidney transplant**

Our Volunteers Help Us Help Our Patients

We offer a HUGE thank you to Rebecca Woods of Tulsa, Oklahoma. Rebecca, a transplant recipient with chronic kidney disease, contacted the APD to ask how she could volunteer to help in our mission. She was instrumental in contacting the American Association of Kidney Patients (AAKP) to submit the story of Matt Jones, the altruistic donor from Petoskey, Michigan, who began the very first Never-Ending Altruistic Donor (NEAD) chain. Watch for Matt's story in an upcoming issue of *RENALIFE*.

APD is a non-profit 501(c)(3) organization that has been created to serve kidney patients through a multi-faceted approach: education, charitable gifts, and ongoing development of paired donation technology.

Many of you have asked how you can help the Alliance for Paired Donation™. There are several ways you can help.

One of our goals is to relieve the donors and patients from shouldering the financial burden that accompanies kidney transplant. There are travel expenses and possible medical costs as well as lost wages.

Your **contributions** to the Alliance for Paired Donation are tax deductible and

will help support patients and donors. For your financial contribution during March or April, you will receive a **"Donate Life"** pin.

You may make a donation securely online through www.paireddonation.org, or you may send a contribution to the Alliance for Paired Donation, Inc., 3661 Briarfield Blvd., Suite 105, Maumee, Ohio 43537. The APD deeply appreciates your generosity.

We need **volunteers** to spread the word about the Alliance for Paired Donation™.

You may contact us for brochures and information that you can distribute to the nephrologists and health care professionals in your area. Give the information to the dialysis centers, social workers, other kidney patients, family members and friends.

Let patients and donors know that they can register on-line for paired donation at www.paireddonation.org, or they can complete the form on the back of this newsletter and return it by mail.

Our staff will contact each person who registers. We can improve every patient's chance of being transplanted with each pair registered.

Receive a "Donate Life" pin with your financial contribution to the APD during March and April

***World
Kidney Day
March 13, 2008***

*A joint initiative of
the International
Society of
Nephrology
and the
International
Federation of
Kidney Foundations*

*Take the
Kidney Quiz*

[http://
www.kidney.org/
kidneyDisease/
kidneyQuiz.cfm](http://www.kidney.org/kidneyDisease/kidneyQuiz.cfm)

Second Chain

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Further tests were done and it turned out that the best match for Ethel's kidney was Mark, who just happened to live in Toledo. "Mark was a patient who was only able to receive a kidney from about one in a hundred people, so finding a kidney for him was like finding a needle in the haystack," said Rees.

Mark received the gift of a kidney and a chance for life from Ethel. Mark's daughter, Andrea, said she is extremely grateful to Ethel and she is anxious to "pay it forward" and donate a kidney to someone else on the Alliance for Paired Donation's list of patients in need of a kidney.



Mail this form to:
3661 Briarfield Blvd.
Suite 105
Maumee, OH 43537
Phone: (512) 961-6199
Email: admin@paireddonation.org
www.paireddonation.org

REGISTRATION FORM

NAME (FIRST) _____ (LAST) _____

ADDRESS _____

CITY _____ STATE _____ ZIP _____

DAYTIME PHONE _____ EVENING _____ CELL _____

E-MAIL ADDRESS _____

What is your interest in Paired Donation?

- I have kidney failure and need a kidney transplant.
- I want to become a kidney donor.
- I need more information. Please call me.
- I am inquiring for a friend or relative.

If you have kidney failure and need a kidney transplant, please select the situation that best applies to you.

- I am on the Deceased Donor Kidney Transplant List.
- My donors have been examined and cleared for donation.
- My donors and I are willing to participate in a paired exchange.
- I need more time to decide if this is right for me.
- I am on dialysis.
- I will be on dialysis soon.

Name of your Kidney Transplant Center _____

If you wish to become a Kidney Donor, this is a serious decision. We have created a companion site to help you make this decision and provide additional information. Please visit www.thenead.com to learn more about Altruistic Kidney Donation. You may also e-mail admin@paireddonation.org.

- I would prefer that the information be mailed to me.

If you need more information or have a comment, please enter your question below and we will contact you as soon as possible.

- I would like to know more about your volunteer opportunities.
- I would like to help financially with a contribution of: \$ _____. Please make checks payable to the **Alliance for Paired Donation**. You will receive a taxdeductible receipt. To donate securely online go to www.paireddonation.org and click "Make Contribution". Thank you.