

Alliance for Paired Donation™ Newsletter

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Serving Kidney Patients Through Technology, Education and Generosity

One man begins a chain of extreme acts of kindness

“I thought that if I could help one person live a decent life, that would be great. It’s turned out to be a lot more than that,” said Matt Jones of Petoskey, Michigan.

On July 26, 2007, an extreme act of kindness saved the life of a 53-year-old grandmother from Arizona. But it did not stop there. That same act of kindness is continuing to save more lives. Barbara, whose kidneys were failing, received a new kidney from a generous stranger, Matt Jones.

The following week, Barbara’s husband traveled to Toledo, Ohio and donated one of his kidneys to a 32-year-old woman, Angela, who had been receiving dialysis for 11 years. Now Angela is free to live a more normal life.

Still, the story does not stop there. Weeks later, Angela’s mother, Laurie,

traveled to Columbus, Ohio, and donated a kidney to Cecilia, and Cecilia’s daughter Linda, gave a kidney to George.

Soon, George’s sister will be the next donor in a chain of transplants.

The Alliance for Paired Donation™ was able to find these matches through a sophisticated computer program.

In effect, Matt, is an altruistic donor who has started the very first never-ending chain of kidney transplants. And every donor in the chain is helping their loved one indirectly by “paying it forward” and directly helping a stranger.

The Alliance for Paired Donation™ is a world leader in developing novel strategies to overcome the shortage of donor organs.

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Notes from the CEO

Welcome to the first edition of the **Alliance for Paired Donation Newsletter**.

The Alliance was formed in 2006 to develop strategies to dramatically increase the number of kidney transplants in the United States by matching willing but incompatible living donor/recipient pairs with other such pairs across the U.S. , in effect, creating a kidney swap.

Michael A. Rees, MD, PhD

The Alliance now has partnered with over 50 transplant centers in 20 states. It is estimated that paired donation will one day allow for an additional 3,000 living donor renal transplants per year in America, greatly increasing the number of living kidney donors. Of all the advances made in renal transplantation in the last 25 years, paired donation has

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Kidney paired exchange will make it possible to perform up to 3,000 additional transplants each year.



On the web at www.NEAD.com

Paying it forward at a later date allows the family members to be with their loved one on the day of transplant.

Did You Know?

- Currently one in nine adults in the US has kidney disease; that equates to 20 million people.
- Over 100,000 people begin dialysis each year.
- 73,531 people are on a waiting list for kidney transplant.
- More than 17,000 kidney transplants are performed each year. Only 6,400 of those are living donor kidneys.
- With kidney paired exchange and altruistic donors, it is possible to perform 2,000 to 3,000 additional transplants each year.
- One altruistic kidney donor can start a chain of transplants saving many lives.
- Of all the advances made in renal transplantation in the last 25 years, paired donation has the greatest potential to extend the lives of patients with renal disease.
- The average patient with end stage renal disease will live 10 years longer if they receive a kidney transplant versus staying on dialysis.

Never-Ending Altruistic Donor Chains

A recent innovation called the “Never-Ending Altruistic Donor” (NEAD™) allows for the novel use of kidneys from a non-directed living donor—someone who gives a kidney without being paired with a loved one who needs a kidney.

Using altruistic donor kidneys to start a NEAD™ chain allows the opportunity for willing but incompatible donors to “pay it forward”. In this way, the altruistic donor starts the chain by giving a kidney to

a recipient, whose incompatible donor then returns the favor by donating to someone else. (see the feature story on page 1.)

Paying it forward at a later date allows the family members to be with their loved one on the day of transplant, rather than undergoing surgery in a simultaneous paired exchange.

For more information go to the website www.theNEAD.com.

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has the greatest potential to extend the lives of patients with renal disease.

The Alliance for Paired Donation™ is a network of transplant centers throughout the United States that have partnered to cooperatively list any kidney patient who has a willing donor who is not a compatible match to that patient. By pooling these patients and donors in

a computer system, compatible matches can be identified and, thus, those patients can receive transplants and others will move up the waiting list more rapidly.

To see which transplant centers are Alliance partners go to our website www.paireddonation.org.

There are many ways to help the Alliance

Many of you have asked how you can help the Alliance for Paired Donation™ .

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.

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.

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

One man begins a chain

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This story about the world's first Never-Ending Altruistic Donor (NEAD™) chain was featured as a large page 3 article in the *USA Today* on July 27, 2007 and in the *Arizona Republic*. It was also featured on *ABC World News with Charles Gibson* on July 26.

The continuing chain of transplants were featured on *NBC Nightly News with Brian Williams* on September 17, 2007.

The gift continues because one man donated his kidney simply because he

Briarfield Blvd., Suite 105, Maumee, Ohio 43537. The APD 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.

could and he had the desire to change just one life. Now his gift continues to change many lives.

"We now know that using altruistic donors to start a chain of transplants works." said Michael A. Rees, M.D., CEO/Medical Director of the alliance for Paired Donation. "Kidney paired donation itself is not experimental and we have the capability to build a sophisticated computer system to have a true national matching system."

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

National Donor Sabbath

November 9-11

Celebrate the miracle of organ and tissue transplantation.

Endorsed by the US Department of Health and Human Services, faith communities throughout the nation will raise awareness about transplantation and the critical need for and the life-affirming gift of, organ donation.

For more information, www.OrganDonor.gov

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Mail this form to:
3661 Briarfield Blvd.
Suite 105
Maumee, OH 43537
Phone: (512) 370-1501
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.

I 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.

Thank you for your interest in the Alliance for Paired Donation™.