



# RENAL OUTREACH

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## TRANSPLANTATION: BE INFORMED ABOUT HIGH RISK DONORS

In November 2007 it was found that four transplant patients had contracted HIV and Hepatitis C from their organ donor.

The deceased donor tested falsely negative for the viruses and four organs were recovered and transplanted from this donor.

Since this discovery, the organ recipients' transplant centers have been monitoring and treating the patients for these additional conditions.

In view of these events, professionals and patients have been asking the following questions:

1. How did this happen?
2. Could this have been prevented?
3. Did the patients discuss the possible risks of transplantation with their medical team?
4. Did the need for the organ outweigh the risks?

According to The Associated Press, public health officials said this is the first known instance of HIV transmission through organ transplants since 1986.

The Centers for Disease Control (CDC) issued guidelines for transplant professionals to identify and try to minimize the risk of transmission of HIV or any other viruses. The CDC emphasized that the risk of getting any disease from a transplanted organ is less than 0.01 percent.

The CDC also explained that the guidelines do not rule out the use of organs from donors identified as "high risk." High-risk donors are those who have HIV or have been involved in high-risk behaviors, such as drug abuse.

The Organ Procurement and Transplantation Network (OPTN) is reviewing the existing procedures regarding the identification of potential donors and the communication of the risk status to determine if anything more or better can be done for the future safety of transplant patients.

There is often limited time to obtain test results during the donation process and patients need to understand and be prepared for any unforeseen results of transplantation.

There are nearly 98, 000 people waiting for organ transplants. Unfortunately, the supply of kidney donors cannot keep pace with the demand and the waiting list for a kidney can be years.

When events such as the above scenario happen, we are reminded that there are risks with transplantation and that patients need to be advised of the risk factors they face to help them make informed decisions and to have their concerns addressed by the health care team.

Patients have the right to know about the specifics of a potential donor organ and can decide with their medical team if they want to turn down all high risk donors based upon the information known at the time of the transplant call.

You need to be an active part of your medical team and while you are waiting for that call that says there is a potential kidney for you, learn as much as you can about kidney donation.

You can visit the Network Patient Web Site at [www.kidneypatientnews.org](http://www.kidneypatientnews.org) for more information and links to other resources.

## References

Nov. 13, 2007, Associated Press, 4 transplant patients infected with HIV, Experts: Case signals patients' need for more information on donors. Retrieved from the World Wide Web on 11/14/07 from [www.msnbc.msn.com/id/21770889/from/ET/print/1/displaymode/1098/](http://www.msnbc.msn.com/id/21770889/from/ET/print/1/displaymode/1098/)

Nov. 13, 2007, United Network for Organ Sharing, OPTN/UNOS statement regarding HIV and hepatitis C transmission through organ transplantation. Retrieved from the World Wide Web on 11/28/07 from [www.unos.org/news/newsDetail.asp?id=977](http://www.unos.org/news/newsDetail.asp?id=977)

## NATIONAL LIVING DONOR ASSISTANCE CENTER

There is a new federal program to help living kidney donors with hotel, travel and meal costs. The National Living Donor Assistance Center (NLDAC) was created to help donors who want to donate a kidney, but could not because of travel expenses. NLDAC provides up to \$6,000 for hotel, travel, meal and other non-medical travel expenses related to the donor evaluation, donor surgery and donor medical follow-up. Eligible living kidney donors will receive a card (similar to a credit card) to pay for covered expenses.

To participate in this program, the donor and the recipient must be U.S. citizens or lawfully admitted residents. Donor income, recipient income and ability to pay are considered. Visit [www.livingdonorassistance.org](http://www.livingdonorassistance.org).

## SELF-CARE AT THE DIALYSIS CENTER: WHAT'S IN IT FOR YOU? (Part 1)

You do dialysis, but may not feel like you know much about it. How does it work, exactly? What do all those alarms do? Why do you have cramps some days but feel fine others?

Dialysis is so complex that you should just leave it to the pros, right? Wrong!

Here are 3 reasons why it's a great idea to take an active role in your own care:

### 1. Knowledge is Power

Dialysis doesn't have to be a mystery. People call me and say, "Nobody tells me anything!" You've seen how busy your care team is—if they don't know you have questions, you may not get answers. So, ask one question at each treatment.

Learn how to weigh yourself, take your blood pressure, or figure out your fluid goal. You'll feel good about yourself—and be less scared.

### 2. You Can Prevent Mistakes

Nobody is perfect. If you learn how your treatments should be done, you can be on the alert and keep mistakes from being made. You just might save your own life one day.

### 3. Nobody Does it Better

You are the only person on earth who can feel both sides of the needles in your fistula or graft. So, if you can reach and are able, you can put in your needles better than anyone else. Doing it yourself hurts less (because you're distracted) and your access can last for years or even decades. Plus, you don't have to worry about who takes care of you, which makes it easier to travel.

One patient put it this way, "Dialysis is a job for my care team, but it's life for me." Taking an active role in your care can help you feel your best.

By Dorian Schatell, Executive Director of the non-profit Medical Education Institute, which has many free resources at [www.kidneyschool.org](http://www.kidneyschool.org), [www.homedialysis.org](http://www.homedialysis.org), and [www.lifeoptions.org](http://www.lifeoptions.org).

**Next time, Watch for  
Part 2 -  
Self-care Options at Home.**

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## “HERO” OF FISTULA LONGEVITY

John Horath (pictured below) has been a dialysis patient for 35 years, having starting dialysis at the age of 21 at Barnes Hospital in St. Louis in 1972. He dialyzed at Mt. Vernon, Illinois for several years then transferred to the Effingham, Illinois facility, now Effingham DaVita, in 1977.



In 2005 his dialysis facility bestowed upon him the honor of a “Hero Award,” one of three given that year nationwide, among his fellow patients.

Even more remarkable, John was recently named one of the three winners in DaVita’s nationwide contest for fistula longevity.

***John has had his original fistula, only once revised, for 35 years!***

A celebration was held in his honor last fall at the Effingham DaVita facility. Many family members and friends stopped by to congratulate John on his outstanding and remarkable achievement. John also received accolades from state Senators and Representatives, as well as from Effingham’s Mayor!

John is an active participant in his care and monitors his venipuncture sites in addition to keeping track of his lab values and blood pressure readings.

He does not shorten or miss treatments and takes medications as prescribed. He is always willing to share his story with students, new patients, and physicians.

John is an inspiration to many of his fellow patients and his longevity on dialysis truly exemplifies the success of “Fistula First!”

Arteriovenous Fistulas (AVF) are the gold standard for vascular access. **Fistula First** is a Centers for Medicare and Medicaid Services (CMS) initiative to meet the The National Kidney Foundation (NKF) Kidney Disease Outcomes Quality Initiative (KDOQI) national practice guidelines which recommend that greater than 65% of hemodialysis patients have a functioning AVF.

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## HOW THE NETWORK CAN HELP PATIENTS AND STAFF

A special thank you to the 577 people who completed the “How Can We Help?” form in the last issue of the *Renal Outreach*. The Patient Services Department wants to hear from patients, family members and facility staff about the kinds of information they would like to receive more of and in what form they would like to receive it. It uses the feedback to determine the resources and materials that are developed.

Overall, 52% of the individuals who completed the form were patients and 6% were family members. The rest were received from staff.

The topics chosen most often for more information by patients included information on transplants (39%), treatment options (31%), self-care (23%), dialysis at home (21%) and end-of life (20%).

Family members would like more information about treatment options (44%), dialysis at home (38%), transplants (35%), self-care (32%), and volunteer work (30%).

You will find articles on some of these topics in this issue of the newsletter and other topics will appear in future issues.

It seems that very few patients receive the *Renal Outreach* at their home and there are still lots of people who do not even know about this newsletter. We encourage you to sign up to receive it at home if you usually read it at the dialysis unit and to share it with others when you are finished with it.

Subscriptions are free! A subscription form is included in this issue (see p.8) and you can now sign up by email and we will let you know when it is available online.

Approximately 57% of patients and family members reported that they have access to a computer and 54% of them have access to the Internet.

Most patients and family members, however, do not know about The Renal Network’s patient Web site, [www.kidneypatientnews.org](http://www.kidneypatientnews.org). Only 6% of them stated they had been to the Web site in the last year.

Our Web site is being updated and we encourage you to visit it! We will be adding more information about the topics you requested on the patient Web site. You also can look at past issues of the *Renal Outreach* online and you’ll find links to many other resources that may be helpful to you. Your comments and suggestions are always welcome!

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## RECIPIENTS OF THE RENAL NETWORK 'ROBERT FELTER MEMORIAL AWARD'

Robert Felter was a tireless advocate for patients and patient education. As a renal patient for over twenty years, he inspired many patients and staff to do more for patients. He also was a champion volunteer for the Network and served on many of its committees. After his death, The Renal Network started a memorial award in his honor. This year, Dirk Combs and Guy Tibbels were chosen as the award winners. Winners attend a conference of their choice that relates to kidney disease.



Guy Tibbels (pictured above) is has been an active member of the Patient Leadership Committee since 2002. He was dialysis for only two and a half months before he received his transplant in 1994. Guy is always willing to participate on whichever PLC subcommittee needs him.

Guy provides charter-fishing trips on Lake Erie during the summer months and is actively involved in the care of his two young children. He wrote an article for the Network's newsletter on Role Reversal a few years ago. As a recipient of this award, Guy plans to attend a conference later this year that focuses on transplant topics.

It is with great sadness that we share that Dirk Combs (pictured below) passed away in May, two months after



he received the award. Dirk had been an active member of both the Board of Trustees and the Patient Leadership Committee since 2001. His positive attitude and his perspective on issues were always appreciated at meetings. Although Dirk received a kidney transplant in July 1993, he had been back on dialysis since 2000. Dirk was a high school swimming official, the treasurer on the board of his local YMCA, and a volunteer for the Indiana Organ Procurement Organization. He will be missed by all who knew him.

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## MANAGE THIRST—FIRST!

In the summertime, many people find it hard to limit their fluid intake. Keeping your fluid intake under control is key to comfort and health. Low fluid weight gains will help your blood pressure and breathing, improve your energy level, and will make your dialysis treatment more comfortable.

In hot weather, resisting extra fluids may seem like an impossible dream. You may feel more thirsty because of the heat and humidity, but there are some things you can do to stay comfortable and in control.

1. Stay away from high sodium foods. Sodium not only makes you thirsty, but “holds” water on your body. At picnics, go for the hamburger or grilled chicken, instead of hotdogs or kielbasa; try carrots and celery instead of pickles, olives and salty snack foods (like chips, cheese curls, etc.).
2. The thirst you experience may be dry mouth, or “off” taste in your mouth. Drinking a glass of water will not make the thirst go away. Instead, try moistening your mouth with lemon flavored ice cubes, or changing the flavor of your mouth with strong mints, hard candy, or lemon wedges.
3. Cold or frozen foods may satisfy your thirst better than warm foods. Try crushed ice sprinkled with lemon crystals instead of coffee. Suck on frozen blueberries or frozen grapes.
4. Sweet foods can make you thirsty. Instead of apple pie, try a tart apple; instead of peach nectar, try lemonade.
5. Although ice is a fluid, it may be more satisfying than an equal amount of water. Use ice cube trays with a measured amount of liquid to help keep from going overboard. Flavor the ice with something tart (like lemon or lemonade), which can help stimulate your salivary glands.
6. Don’t forget “hidden fluids”. Gelatin salads and watermelon should be considered fluid. (Why do you think they call it *watermelon*?).
7. Don’t use sports drinks. All sports drinks contain salt (potassium and phosphorus!) It is not necessary to replace salt lost with normal sweating. Many “designer waters” also contain nutrients that you should avoid.
8. Keep cool! Stay in the shade, by a fan, or in air conditioning as much as possible. Use a cold, wet washcloth to cool off your face, neck and hands.
9. If you are diabetic, keep your blood sugar in good control. High blood sugar will make you thirsty; the solution is to get it down to normal, and keep it there.
10. Get enough dialysis. When the toxins in your body are too high (due to under dialysis), you will be more thirsty.

Check with your dialysis dietitian to find the right amount of fluid for you. Get into the *habit* of limiting your fluids so that you can enjoy a healthy and safe summer with family and friends.

(By Beth Fry, RD, LD, Member of the Medical Review Board)

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## Subscription Form for the *Renal Outreach*

Dialysis patients are eligible to receive free home delivery of the *Renal Outreach*. To receive the *Renal Outreach* patient newsletter at home, just complete and return the form below to our Patient Services Department. If you already have a subscription, feel free to give the form to a fellow patient or copy this page and distribute to patients on your shift.

### SUBSCRIPTION FORM FOR RENALOUTREACH

NAME: \_\_\_\_\_

FACILITY: \_\_\_\_\_

ADDRESS: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE: \_\_\_\_\_ ZIP: \_\_\_\_\_

EMAIL: \_\_\_\_\_

Please send by  mail  email

Mail to: **Renal Outreach**  
**The Renal Network, Inc.**  
**911 E. 86<sup>th</sup> Street, Suite 202**  
**Indianapolis, IN 46240**

FAX to: **317-257-8291**

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# RENAL OUTREACH

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