Inside this issue:

Transplant: What You Need to Know 1-2
New Technologies: Treatment for PKD 3
Help Protect Your Loved Ones: Do the WAVE 3
On Dialysis How Long? 4-5
Transplant: Financial Help is Available 6
Patient LAN: We Need You! 7
Grievance Process 7
The 2012 Robert Felter Award 8
You Could be the Next Robert Felter Award Winner! 9
Role of the Network 9
What Treatment Option is Best for Me? 10-11
This Month’s Recipe: Holiday Cheese Ball 12

TRANSLANT: WHAT YOU NEED TO KNOW

How do I find out if I am a candidate for kidney transplant?
Express your interest in exploring the option of transplantation with your nephrologist (kidney doctor). Most nephrologists will refer you to a transplant center for an evaluation.

What is involved in the transplant evaluation process?
Your initial meeting with the transplant team may take four to seven hours depending on differences between transplant center protocols:

- An examination by the transplant surgeon.

When will I find out if I am accepted as a transplant candidate?
Soon after your initial evaluation you and your nephrologist will receive a letter that will let you know if you are a potential candidate for transplant. In some cases, based on your medical history, having a transplant might not be an option for you.

What further tests may be needed if I am told that I am a transplant candidate?
Further tests may include:

- Chest X-ray and EKG
- Additional blood work
- Gallbladder ultrasound
- Mammogram (females)
- Test for prostate cancer (males)
- Dental examination

(Continued on page 2)
How long does it take to complete the transplant workup process?
These tests are extremely important and generally take three to six months to complete.

How long will I have to wait for a transplant?
It is not possible to predict waiting time. Waiting time varies between regions of the country. The general average waiting time for a cadaveric kidney is two to five years. In some cases a perfect match may become available and the waiting time would be lessened. If a living donor is available, the transplant would occur as soon as the donor completes a series of tests to assure good health and then the actual surgery date is coordinated.

What are the two kinds of transplant?
Kidneys for transplant may come from a person who has died (a deceased donor), or from a healthy living person, like a family member or a friend who offers to donate a kidney (a living donor)

Who can be a living donor?
A living donor is a volunteer who is physically healthy, does not have kidney disease, and has a blood type that matches the recipient. Donors can be family members, friends, neighbors, or fellow church members of the recipient—anyone that is willing to donate. Donors do not have to be the same race or sex as the recipient.

How long will surgery take?
The operation generally takes two to four hours.

How long will I have to stay in the hospital?
Admission time varies with a range from three to seven days depending on the center’s policy and the person’s readiness for discharge.

What types of medication will I have to take after the transplant?
Again, transplant centers vary. Most use a combination of three anti-rejection medications (to prevent rejection of the foreign organ). Discuss the specifics of medications with your transplant team, as this will be an extremely important part of your long-term care.

How can I learn more about transplantation?
The National Kidney Foundation (NKF) has a toll-free number with free information available. The number is 1-800/622-9010. You may also go to their webpage: www.kidney.org.
NEW TECHNOLOGIES: TREATMENT FOR PKD

A new treatment for individuals with polycystic kidney disease (PKD) has been tested in a recent clinical trial, and now awaits approval by the FDA.

In the clinical trial, the drug tolvaptan was tested over a worldwide 3-year trial on 1,445 randomly assigned patients. Tolvaptan, currently marketed under the name Samsca as a treatment for people who have too much water in their systems, successfully slowed the growth of cyst-filled kidneys while also slowing the resulting loss of kidney function.

FDA approval is a slow process, often taking months or years. Nevertheless, the proven success of the trial is cause for hope.


HELP PROTECT YOUR LOVED ONES: DO THE WAVE

People can get infections in hospitals and other healthcare settings (such as dialysis facilities) while being treated for another condition, since medical procedures can expose patients to certain germs. At any given time, one in 20 hospital patients has a healthcare-associated infection.

Family members and friends who assist in patient care - your “caregivers” - are a member of your healthcare team. Caregivers have an important role in preventing healthcare associated infections.

It’s easy for you to help prevent these infections, by doing the WAVE:

**W**  Wash or clean hands before, during, and after visiting a healthcare facility, such as the dialysis unit or a hospital.

**A**  Ask questions of doctors, nurses, and other healthcare providers. You can improve your or your loved one’s care by taking an active role. Understand the patient’s condition. Evaluate the options.

**V**  Vaccinate against the flu each year, unless otherwise directed by your doctor or other healthcare provider. Ask friends and families who are sick not to visit you.

**E**  Ensure safety by not touching medical equipment unless absolutely necessary. Work with healthcare providers to make sure catheters and other medical devices are properly maintained and removed promptly.

WAVE information adapted from a brochure developed by the Health and Human Services Partnership for Patients. Learn more at www.healthcare.gov/partnershipforpatients.
ON DIALYSIS HOW LONG?

For two patients with kidney disease, this incredible story involves far more than the long hours spent hooked up to life-saving blood-cleansing machines

By Rita Price
THE COLUMBUS DISPATCH
rprice@dispatch.com

Looked at one way, the numbers behind the celebration might seem grim: Two patients, six failed transplants and a combined 63 years of treatment and dialysis. Jerry Mitchell and Julie Boatwright are the faces -- the usually smiling faces -- behind that improbable math.

"You talk to anybody, and they think dialysis is the end of the road," Mitchell said. "I feel good, and they took my kidneys out in 1975."

He and Boatwright were honored yesterday by staff members at Fresenius Medical Care -Mount Carmel West for being "quarter-century patients," which is a festive way of saying that they've had successful, decades-long relationships with the blood-scrubbing machines that keep them alive.

Mitchell, 58, has been a patient for 36 years; Boatwright is 43 and first underwent dialysis 27 years ago.

"It's very unusual," said Dr. Raj Venkataraman, medical director at the center. "But the idea is, you can. You can live many, many years on dialysis and lead a productive life."

Mitchell said he's happy to serve as an example for that message, especially when many people with kidney disease don't receive transplants.

According to U.S. Renal Data System information provided by Fresenius, about 382,000 Americans rely on some form of dialysis for their survival. More than 72,000 are on waiting lists for kidney transplants, but only about 18,000 will receive a new organ each year.

"Some of them are so down in the dumps," Mitchell said of dialysis patients. "I walk in and say, 'Hey, I've been doing this going on 37 years.' They might talk to me, and I give them encouragement."
With 10 siblings, the Grove City man always had a supply of willing donors and good matches for transplants. Brothers gave him kidneys twice, but his disease soon returned. A third transplant failed after his body rejected the kidney.

Boatwright, who lives just outside Grove City, went through three transplants, too. The anguish of those experiences behind her, she also tries to serve as a mentor for other dialysis patients. The usual regimen is treatment three days a week for about four or five hours each time.

"There are, what, 168 hours in a week?" she said. "Don't just dwell on the 15 you've got to spend hooked up to a machine."

Boatwright lobbied for the recent addition of Wi-Fi at the center, and she and Mitchell both offer advice about the importance of keeping to prescribed medications and diet. Dialysis patients must limit fluid intake and be careful about foods high in sodium, potassium and phosphorus.

Center staff members said their two senior patients are model patients.

"It's like a job," Mitchell said.

"You gotta clock in," Boatwright said, laughing.

"And show up," Mitchell said. "Believe it or not, there are people who call in sick."

Both underwent dialysis late yesterday afternoon as usual, but this time there were shiny balloons tethered to their chairs and renal-friendly cake and punch waiting in the reception area.

Mitchell read newspapers on his iPad and kept watch over the machine. He has long studied the science and engineering behind its every beep, pump and whirl.

"Never had a blue balloon before," he said.

Boatwright said staff members once gave out little prizes for patients who, because they were taking good care of themselves, had great lab reports.

She smiled and declined the offer.

"Nope," Boatwright said. "Life is good enough."

Photos courtesy of Photographer Shari Lewis and The Columbus Dispatch. Above: Julie Boatwright, right, is congratulated by Bernadette Venkataraman during a celebration honoring her as a "quarter-century" dialysis patient at Fresenius Medical Care-Mount Carmel West. Opposite page: Jerry Mitchell reads on his iPad during dialysis at Fresenius Medical Care-Mount Carmel West. Mitchell has been a dialysis patient for 36 years.
TRANSPLANT: FINANCIAL HELP IS AVAILABLE

The article below is excerpted from “Caregiver” - a quarterly supplement to Trib Total Media. By Gen Lucidi Payne. Summer 2012

Transplant costs vary according to organ type and hospital. When testing, surgery, recovery and other expenses are tallied, the bill is substantial. In 2011 the average cost for one kidney was about $263,000.

Insurance companies typically pay only 80 percent of hospital-related charges. Some insurance plans have caps on the amount paid over a lifetime. Many transplant candidates are also covered by Medicare, Social Security or Veterans benefits, all of which have payment restrictions.

As a result, transplant recipients and their families generally rely on various types of financing to help pay the uncovered costs associated with organ transplants, such as medication, ongoing medical visits, and personal expense families incur traveling to hospitals.

Listed below are some organizations which offer help. Please visit the Network website for additional resources.

**AMERICAN KIDNEY FUND**
800-638-8299
helpline@kidneyfund.org
www.akfinc.org
Provides grants to needy dialysis patients, kidney transplant recipients and living kidney donors for health-related transportation and medication expenses

**CHILDREN’S ORGAN TRANSPLANT ASSOCIATION**
800-366-2682
cota@cota.org
www.cota.org
Raises funds for individuals and families for transplants, living donors

**MEDICARE HOTLINE**
800-Medicare (633-4227)

**NATIONAL FOUNDATION FOR TRANSPLANTS**
800-489-3863 (toll free)
info@transplants.org
www.transplants.org
Provides financial assistance and advocacy to transplant candidates and recipients

**NATIONAL LIVING DONOR ASSISTANCE CENTER**
703-414-1600 / 888-870-5002
NLDAC@livingdonorassistance.org
www.livingdonorassistance.org
Provides financial assistance to those who want to donate an organ

**NATIONAL TRANSPLANT ASSISTANCE FUND**
800-642-8399 or 610-727-0612
info@ntafund.org
www.ntafund.org
Empowers people to raise money in their communities to cover uninsured medical expenses
PATIENT LAN: WE NEED YOU!

Would you like to volunteer to be a part of Network activity on behalf of patients and family members?

The Renal Network is looking for both patient and family members to participate in a Patient Engagement Learning and Action Network (LAN). This group will identify needs of kidney patients and then help the Network to develop educational materials to address these needs.

The group will meet either in person or by telephone conference call four times a year.

If you would like to lend your skills and expertise to this group, please contact The Renal Network for more information at:

Network 4 (PA / DE):
800-548-9205

Network 9/10 (IL / KY / OH / IN):
800-456-6919

GRIEVANCE PROCESS

A patient grievance is a formal complaint about a situation, event, or condition involving a person receiving End Stage Renal Disease (ESRD) care or services. Each ESRD facility is required to have a procedure for resolving patient grievances. A grievance can be filed by a patient, or their representative, without restraint or interference and without fear of discrimination or reprisal.

If an ESRD patient feels that a grievance has not been adequately addressed at the facility level, or chooses not to use the facility grievance process, the patient may file a grievance with The Renal Network (ESRD Networks 4, 9, and 10). All grievances and the deliberations connected to them are confidential.

The Renal Network may: act as a facilitator/coordinator; directly investigate the grievance; or refer the concern to a more appropriate agency. Responding to individuals with ESRD who have concerns regarding quality of care, access to ESRD services, and rehabilitation is a high priority at The Renal Network.

If you think you may have a grievance or want to have a confidential discussion about a situation, event, or condition involving your ESRD care or services, you may call The Renal Network:

Network 4 (PA / DE):
800-548-9205

Network 9/10 (IL / KY / OH / IN):
800-456-6919
THE 2012 ROBERT FELTER AWARD
By Michael Turner

I was diagnosed with stage 5 kidney failure in 1990. Since then, I have been a Peritoneal Dialysis patient for 10 years, and I have had a successful transplant that lasted for 7 years. For close to 7 years, I have been receiving in-center hemodialysis treatment.

As a patient I’ve become very active in my unit. I have sponsored outings, planned a facility Bar B Que, and an annual patient Christmas Party. One of the biggest things I take to heart is when any of us have a concern at our unit I’ll bring it to the medical director and the health care team.

Early this year I had the pleasure of attending the patient empowerment meeting in Indianapolis, Indiana. The theme was “Whose Life Is It Anyway?” I found the meeting to be very interesting and motivating. I wish more people would attend and hope we can get more people to these meetings in the future.

One of the most amazing things that happened to me at my unit was being named the Robert Felter Memorial Award recipient of 2012. I was so touched to win this award and my heart goes out to The Renal Network and its staff for this honor. As the Award winner, I attended the American Association of Kidney Patients (AAKP) annual conference in Atlanta, Georgia. This was my first visit to the Conference, and it truly won’t be the last one I attend.

Here are some of the sessions I attended:

- Welcome Reception in the Exhibit Hall: Members of the AAKP board of directors and featured exhibitors from the renal community were available to meet with patients and other participants.
- The 2nd annual public Policy Forum: John Rother, CEO and President of the National Coalition on Health Care, America’s oldest and most diverse group, spoke.
- Julie Barnes, Director of the Bipartisan Policy Center. Julie has years of experience working with health care policies as a health care attorney.
- There also were opportunities to ask questions and so many people had the same questions. I found the forum to be very informative and the speakers knowledgeable in regard to the needs of the renal family.
- “Maintaining a Healthy Life through Diet and Nutrition”
- AAKP Annual Award Banquet, “A Night of Inspiration”, which I found to be a very moving experience.

I wish everyone could attend this conference. It provides many learning opportunities and explores what kidney disease patients face on a day-to-day basis and how they cope with their disease.
YOU COULD BE THE NEXT ROBERT FELTER AWARD WINNER!

The Renal Network, Inc. takes great pride in offering kidney patients the opportunity to apply for the **2013 The Robert Felter Memorial Award** in honor of Robert Lee Felter. Mr. Felter was a mentor, patient advocate, friend and a guiding force for what The Renal Network has accomplished.

Applications for **The Robert Felter Memorial Award** will be e-mailed to dialysis facilities and transplant centers in January 2013. The Network is encouraging staff and patients to work together to complete the application and for the staff to write a recommendation letter. The winners will be able to attend an expense paid kidney-related national or local educational conference.

Nomination forms will be sent to facility social workers in January and will be on the Network web site. If you would like to receive an application directly, contact Katie Stark at The Renal Network at 800-456-6919.

So many kidney patients have learned to live successfully with kidney disease while also helping other patients on their journey to adjustment and acceptance. If you are one of those remarkable patients, please apply for **The Robert Felter Memorial Award**.

ROLE OF THE NETWORK

The Renal Network, Inc. (ESRD Networks 4, 9, & 10) serves as a partner with the Centers for Medicare & Medicaid Services (CMS), dialysis and transplant providers, as well as the chronic kidney patients under their care. The Renal Network provides quality improvement, data management, complaint investigation, technical assistance, and patient/professional educational services for more than 1,000 providers and greater than 60,000 individuals living with chronic kidney disease in our six-state geographic region (Delaware, Pennsylvania, Ohio, Indiana, Illinois, and Kentucky). Our goal is to effectively increase the care and quality of life for ESRD patients.
WHAT TREATMENT OPTION IS BEST FOR ME?

Everything in life has “a good side” and a “not so good side”. Treatments for kidney failure are the same way. Every treatment has pros (good things) and cons (things you may not like). Every person sees things differently. Something that you don’t like may be a good thing for another person. Throughout this article, we will provide the pros and cons of In-Center Hemodialysis, Home Hemodialysis, and Peritoneal Dialysis (both CAPD and CCPD).

### In-Center Hemodialysis

<table>
<thead>
<tr>
<th>Some of the Pros of In-Center Hemodialysis</th>
<th>Some of the Cons of In-Center Hemodialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You have trained professionals with you at all times.</td>
<td>• Staff who are not familiar with your fistula or graft may put in your dialysis needles.</td>
</tr>
<tr>
<td>• Medical help is available quickly if there is an emergency.</td>
<td>• You must follow clinic rules - for example, eating/no eating and limits on the number of visitors you can have during your treatment and when they can visit.</td>
</tr>
<tr>
<td>• You can meet and talk with other people on dialysis. Dialysis is a social time for many people.</td>
<td>• Your treatments are scheduled by the center.</td>
</tr>
<tr>
<td>• There is no machine to take care of and store.</td>
<td>• You must travel to and from the center for treatments.</td>
</tr>
<tr>
<td>• Your treatments are only 3 times a week.</td>
<td></td>
</tr>
</tbody>
</table>

### Home Hemodialysis

<table>
<thead>
<tr>
<th>Some of the Pros of Home Hemodialysis</th>
<th>Some of the Cons of Home Hemodialysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You can choose the time of day you want to dialyze. However, you will still have to dialyze for the ordered number of hours and days.</td>
<td>• You need a partner.</td>
</tr>
<tr>
<td>• You don’t have to travel to and from a dialysis center 3 times/week.</td>
<td>• You and your partner need to be trained for home dialysis.</td>
</tr>
<tr>
<td>• A home dialysis nurse is on call to answer questions or help you with any problems you may have with the dialysis treatment.</td>
<td>• You have fewer chances to meet and talk with other people on dialysis.</td>
</tr>
<tr>
<td>• You have more control over your treatment and your life.</td>
<td>• You need room to store the machine and supplies at home.</td>
</tr>
<tr>
<td>• You have more independence.</td>
<td>• You have to order the necessary supplies for your treatments.</td>
</tr>
<tr>
<td>• You decide if and when you want to eat or have visitors.</td>
<td>• You will need to call paramedics for medical help if you have an emergency that you can’t solve.</td>
</tr>
<tr>
<td>• The same person helps you with your dialysis</td>
<td>Learning how to handle dialysis emergencies is a big part of the home hemodialysis training.</td>
</tr>
</tbody>
</table>
## Continuous Ambulatory Peritoneal Dialysis (CAPD)

<table>
<thead>
<tr>
<th>Some of the Pros of CAPD</th>
<th>Some of the Cons of CAPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You don’t have to travel to and from a dialysis center 3 times a week.</td>
<td>• Not everyone can do CAPD.</td>
</tr>
<tr>
<td>• There are no needles.</td>
<td>• Exchanges need to be done every 4-6 hours during the day.</td>
</tr>
<tr>
<td>• The diet is not as strict as the hemodialysis diet.</td>
<td>• Your abdomen is always full of fluid.</td>
</tr>
<tr>
<td>• You can do the dialysis yourself.</td>
<td>• You have a catheter in your abdomen.</td>
</tr>
<tr>
<td>• You can do dialysis at the times that you choose. However, to make sure that you get enough dialysis, you will still have to do the ordered number of exchanges every 4-6 hours during the day.</td>
<td>• The dialysis steps need to be done carefully to prevent infection.</td>
</tr>
<tr>
<td>• You don’t need a machine to do CAPD.</td>
<td>• There is a chance you could get an infection of the peritoneal cavity.</td>
</tr>
<tr>
<td>• CAPD supplies are delivered to your home.</td>
<td>• You need a place to store dialysis supplies.</td>
</tr>
<tr>
<td>• It’s easy to do CAPD when you travel. Supplies can be sent to a vacation address.</td>
<td></td>
</tr>
<tr>
<td>• You have more control over your treatment and your life.</td>
<td></td>
</tr>
<tr>
<td>• A home dialysis nurse is on call to answer questions or help you with any problems you may have with your dialysis treatment.</td>
<td></td>
</tr>
</tbody>
</table>

## Continuous Cycling Peritoneal Dialysis (CCPD)

<table>
<thead>
<tr>
<th>Some of the Pros of CCPD</th>
<th>Some of the Cons of CCPD</th>
</tr>
</thead>
<tbody>
<tr>
<td>• You don’t have to travel to and from a dialysis center 3 times a week.</td>
<td>• Not everyone can do CCPD.</td>
</tr>
<tr>
<td>• There are no needles.</td>
<td>• You need to spend the nightly dialysis time in bed.</td>
</tr>
<tr>
<td>• The diet is not as strict as the hemodialysis diet.</td>
<td>• You may feel tied down to the machine at night.</td>
</tr>
<tr>
<td>• You can do the dialysis yourself.</td>
<td>• Your abdomen is always full of fluid.</td>
</tr>
<tr>
<td>• CCPD supplies are delivered to your home.</td>
<td>• You have a catheter in your abdomen.</td>
</tr>
<tr>
<td>• You can decide when to start your nightly dialysis treatment. However, to make sure you get enough dialysis, you will still have to get the prescribed number of hours and exchanges during the night.</td>
<td>• The dialysis steps need to be done carefully to prevent infection.</td>
</tr>
<tr>
<td>• The dialysis treatment is done at night while you sleep.</td>
<td>• There is a chance you could get an infection of the peritoneal cavity.</td>
</tr>
<tr>
<td>• You don’t have to do exchanges every 4-6 hours daily.</td>
<td>• If you have a dialysis problem during the night, the machine alarms will wake you up to fix the problem.</td>
</tr>
<tr>
<td>• You can switch to CAPD when you travel so you don’t have to take your machine with you. Supplies can be sent to a vacation address.</td>
<td>• You need a place to store the dialysis machine and supplies.</td>
</tr>
<tr>
<td>• You have more control over your treatment and life.</td>
<td>• You have fewer chances to meet and talk with other people on dialysis.</td>
</tr>
<tr>
<td>• A home dialysis nurse is on call to answer questions or help you with any problems you may have with your dialysis treatment.</td>
<td></td>
</tr>
</tbody>
</table>
HOLIDAY CHEESE BALL

*Diet type: Vegetarian*

**INGREDIENTS**
- 8 ounces cream cheese, softened
- 1/4 cup Catalina or Russian Salad Dressing
- 1 teaspoon onion powder
- 1/3 cup finely ground walnuts
- Apple slices
- Low sodium crackers

**DIRECTIONS**
- Combine cream cheese, salad dressing, and onion powder in a medium bowl.
- Place in refrigerator for 30 minutes to chill.
- Form cheese mixture into a ball.
- Place ground walnuts on a plate and roll cheese ball to cover.
- Wrap in plastic wrap and chill until ready to serve.
- Serve cheese ball with low sodium crackers and apple slices.

**Nutrient Analysis**

<table>
<thead>
<tr>
<th>Nutrient</th>
<th>Servings per recipe</th>
<th>Serving size</th>
<th>Calories</th>
<th>Protein</th>
<th>Total Fat</th>
<th>Sodium</th>
<th>Phosphorus</th>
<th>Potassium</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12</td>
<td>1-1/2 tbsp</td>
<td>140</td>
<td>2 g</td>
<td>13 g</td>
<td>131 mg</td>
<td>32 mg</td>
<td>55 mg</td>
</tr>
</tbody>
</table>

Renal and Diabetic Exchanges: 1 and one-half fat, one-half milk

This content is reprinted from the December 2009 issue of AAKP Diet Tips & Bits with permission from the American Association of Kidney Patients (AAKP). Opinions expressed by the authors are not necessarily those held by AAKP, its Board of Directors or publisher. The American Association of Kidney Patients is a national non-profit organization that exists to improve the lives of fellow kidney patients and their families by helping them to deal with the physical, emotional, and social impact of kidney disease. For more information about AAKP, visit www.aakp.org.