



# RENAL OUTREACH

**ESRD Network 9/10**

**Summer 2005/Vol XV, No.2**

## Robert Felter Memorial Awards

In May 2002 this award was created and dedicated to the memory of Mr. Felter, a long-time Network volunteer and a tireless advocate for the renal patient. Winners for the 2005 awards were announced at the Awards Luncheon held during the Annual Nephrology Conference.

This award is presented in two parts. The Patient Award is given to a patient who is actively involved on a Network committee and is dedicated to the betterment of renal patients.

The second award is presented to a dialysis facility or transplant center that has developed a creative proposal to enhance the quality of life for their patients.

### **Patient Award: Lorraine Edmond Gary, IN**



Lorraine Edmond is pictured above with her award.

Lorraine Edmond is a mother of five and a grandmother to eight. She loves volunteering and has done so in her community for many years. In 1992, she was diagnosed with ESRD, and has been involved with The Renal Network over a period of 12 years.

She began in 1993 as a Patient Advisory Council (PAC) representative at her facility. She has been trained as a Patient to Patient volunteer. In 1994 she became an active member of the Patient Leadership Committee (PLC) and continues to serve in that capacity today. In 2003 she was appointed to the Medical Review Board and serves on the Patient Relations Subcommittee.

Lorraine started a renal support group at her facility that meets every month and has facilitated parties, luncheons, and picnics for the facility patients. She remains a strong advocate and supporter of The Renal Network, and the renal community. As the recipient of this award, Lorraine will attend the AAKP Conference in Las Vegas, Nevada in September.

### **Facility Award: Renal Care Group – University Program Chicago, IL**

The award will be used to help publish the cookbook, “Real Cooking for Renal Patients.” The facility serves a large culturally and socio-economically diverse population and foods are a personal, social, and cultural part of everyone’s life.

This project encourages patients, family, and staff to share their tried, true and traditional recipes that others may enjoy through a cookbook.

The cookbook that will be distributed to patients, family, and staff as well as new patients starting at the facility.

Accepting the award on behalf of RCG University Program Chicago is Laura Gripman, MS, RD, facility dietician and the primary contact for the project.



Pictured above is Laura Gripman (left) and Susie Stark, Executive Director of The Renal Network, Inc. (right).

## The President's Award

The President's Award is a special honor given to recognize contributions by individuals to The Renal Network.

The President's Award was presented to Evernard "Bill" Davis a long-time polycystic kidney disease patient and tireless patient advocate. It is with gratitude and great pleasure that the Network recognizes his contributions, and wishes him well as he retires from Network service in 2005.

Mr. Davis has served with dedication, patience and good cheer since he joined the ESRD Network program in 1980.

For over 25 years, Mr. Davis has been at the forefront Network patient activities and has helped to shape many of its educational and outreach programs.

Mr. Davis played a key role in the development of the Patient Advisory Council (PAC) and has remained a patient representative throughout his many volunteer service roles with the Network. His most cherished role is working one-on-one with fellow patients seeking advice and comfort, especially those newly-diagnosed.



Pictured above (from left to right) is Dr. Douglas Maxwell, Bill Davis, Susie Stark and Dr. Jay Wish.

Mr. Davis has also held positions on the Patient Leadership Committee, the Medical Review Board and the Board of Trustees. He is steadfast in presenting the patient perspective with honesty and objectivity.

Dr. Jay Wish, Network President, presented the award and Dr. Douglas Maxwell, Mr. Davis' nephrologist, toasted his many contributions and accomplishments.



Mr. Davis' mother, Anna Lee Davis, (left) and Marietta Gurnell (Network staff in center) join Mr. Davis during Award's Luncheon celebration.

## Are You Thinking About A Kidney Transplant?

Patients with kidney failure have a variety of treatment options available to them — in-center or home hemodialysis, peritoneal dialysis (CAPD or CCPD) or transplantation. Patients interested in receiving a kidney transplant must first find out if they are eligible candidates. According to the federal regulations developed by CMS for ESRD services, all patients need to be informed if they are or are not eligible for a transplant.

Patient eligibility for a transplant is determined by a series of examinations and tests. Patients may not be eligible for a transplant for a variety of reasons. Some fairly common reasons for excluding a patient from having a transplant would be a recent cancer, an active infection or un-correctable heart, lung or liver problems. Other reasons could include compliance issues, smoking, and weight problems. Patients excluded from a transplant for correctable conditions may work to become eligible. Some of the things patients could be asked to do to become eligible for transplantation are to stop to smoke, lose weight, exercise and stay infection-free. Patients interested in receiving a transplant should talk to their nephrologist and visit local transplant centers. Admissions criteria may vary. So be sure to ask each transplant center for information about their policies and procedures.

TRANSPLANT CENTER	City	Phone Number
<b>Kentucky</b>		
Jewish Hospital	Louisville	502-587-4178
University of Kentucky Medical Center	Lexington	859-323-1691
<b>Illinois</b>		
Childrens Memorial Hospital	Chicago	773-880-6363
Foster McGaw Hospital of Loyola	Maywood	708-216-3454
Memorial Medical Center	Springfield	217-788-3441
Northwestern Memorial Hospital	Chicago	312-695-8900
Rush Medical Center	Chicago	312-942-4252
St. Francis Medical Center	Peoria	800-635-1440
University of Chicago Medical Center	Chicago	773-834-3537
University of Illinois	Chicago	312-996-0376
<b>Indiana</b>		
Clarian IU	Indianapolis	317-274-4207
Clarian - Methodist	Indianapolis	317-962-8677
<b>Ohio</b>		
Akron City Hospital	Akron	330-375-3041
The Cleveland Clinic Foundation	Cleveland	216-444-8949
Childrens Hospital Medical Center	Cincinnati	513-636-4531
Medical College Hospitals	Toledo	419-383-3578
Miami Valley Hospital	Dayton	937-208-2529
Ohio State University Hospital	Columbus	614-293-6724
St. Elizabeth Health Center	Youngstown	330-480-3642
The Christ Hospital	Cincinnati	513-585-2493
University of Cincinnati Medical Center	Cincinnati	513-584-7001
University Hospitals of Cleveland	Cleveland	216-844-3689

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## Have a problem or a complaint related to your treatment?

**Working together, we can solve this problem!**



**Take action to resolve your concerns. Consider the following:**

- **Speak to your health care team.**

Let them know exactly what is not working for you. Discuss possible solutions. Be sure to include everyone affected. Make a good-faith effort to resolve the problem.

- **Still not satisfied with the outcome?**

Ask your social worker for a copy of your facility's grievance policy. Take the necessary steps to begin the process.

- **Still have questions?**

Then ask for a copy of The Renal Network's grievance process. To receive a grievance packet call (800) 456-6919 or visit our patient Web site, *Kidney Patient News* ([www.kidneypatientnews.org](http://www.kidneypatientnews.org)), to download a grievance packet or for more information. The Network staff also can assist you in resolving your complaints or provide you with additional resources.

The State Department of Health may also be able to help with issues or concerns regarding quality of care.

**If you are concerned about your quality of care, it is important to make your complaints or questions known.**

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## New Home-Hemodialysis Device

“The NxStage *System One* is a portable, lightweight, automated and easy-to-use dialysis machine, intended to be used by healthcare professionals and by trained lay users alike” (excerpt from NxStage Corporate Fact Sheet).

During the past year Clarian Health Partners/Indiana University Medical Center (IUMC) participated in a multi-center study to evaluate the safety of the NxStage Delivery System One in the home dialysis setting.

A poster presented at The Renal Network’s Annual Nephrology Conference in Indianapolis, IN defined the trials and the successes of this home hemodialysis product. The objective of the study at IUMC was to demonstrate that the NxStage Delivery *System One* is as safe and effective as equipment used in a clinical environment.

Therapy frequency is six-seven times a week for about two and one-half hours. The study at IUMC began with nine patients. Eight study patients remain on NxStage at this time, one having received a successful renal transplant.



Nephrology Conference Poster Session

“Universally these patients have expressed an improvement in quality of life regarding post dialysis recovery time, cognitive function, activity level, and overall sense of well being,” stated Dr. Michael Kraus, the study’s principal investigator and medical director of IU’s Continuous Ambulatory Peritoneal Dialysis and Acute Dialysis Units. Based on the initial response of these patients the short daily dialysis was opened to patients not enrolled in the study.



As of May 24, 2005, twenty-six patients at IUMC are on short daily dialysis using the NxStage *System One* Delivery System (shown at left).

This dialysis device has been used in hotel rooms, recreational vehicles, and a cabin on a Caribbean cruise. Many of these patients have increased work productivity or have returned to the work force and an overall decrease in hypertension has been seen.

The study conclusion is that short daily dialysis is a well-received and successful therapy for patients with Chronic Kidney Disease. For more information about the IU daily dialysis program, call 317-274-4428. More information about NxStage can be found at [www.nxstage.com/](http://www.nxstage.com/)

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## Rehabilitation and Employment

Thinking about finding, changing or keeping a job. State Vocational Rehabilitation agencies furnish a wide variety of services to help people with disabilities. Services vary from state to state. Contact the state offices listed below to learn what they offer.

### Illinois (IL)

Department of Human Services  
Office of Rehabilitation Services  
400 West Lawrence  
PO Box 19429  
Springfield, IL 62794  
800-843-6154 (customers)  
800-447-6404 (TTY)  
800-804-3833 (providers)  
Web: <http://www.state.il.us/agency/dhs/>

### Indiana (IN)

Division of Disability, Aging & Rehabilitative Services  
402 W. Washington Street W-453  
PO Box 7083  
Indianapolis, IN 46207-7083  
customers(317) 232-1252 fax (317) 232-6478  
Web: <http://www.state.in.us/fssa/servicedisabl/vr/index.html>

### Kentucky (KY)

Kentucky Department of Vocational Rehabilitation  
209 St. Clair Street  
Frankfort, KY 40601  
1-800-372-7172 (Voice/TDD)  
Web: <http://kydvr.state.ky.us/>  
E-mail: [wfd.vocrehab@mail.state.ky.us](mailto:wfd.vocrehab@mail.state.ky.us)

### Ohio (OH)

Ohio Rehabilitation Services Commission  
400 East Campus View Boulevard  
Columbus, OH 43235-4604  
614-438-1200 (Voice/TTY)  
1-800-282-4536 (Ohio only)  
614-438-1257 (Fax)  
Web: <http://www.rsc.ohio.gov/>

## Feel that you have been denied employment unfairly?

The **Americans with Disabilities Act** gives civil rights protections to individuals with disabilities. It guarantees equal opportunity for individuals with disabilities in public accommodations, employment, transportation, state and local government services, and telecommunications.

Complaints of employment violations by state and local government or by private employers should be filed with the **Equal Employment Opportunity Commission**.

Call 800-669-4000 (voice) or 800-669-6820 (TTY) to reach the field office in your area or contact one of the offices listed below.

### Chicago District Office

500 West Madison Street , Suite 2800  
Chicago, Illinois 60661  
Phone: 312-353-2713 TTY: 312-353-2421

### Indianapolis District Office

101 West Ohio St, Ste 1900  
Indianapolis, IN 46204  
Phone: 317-226-7212 TTY: 317-226-5162

### Louisville Area Office

600 Dr. Martin Luther King, Jr. Place, Suite 268  
Louisville, Kentucky 40202  
Phone: 502-582-6082 TTY: 502-582-6285

### Cleveland District Office

Tower City - Skylight Office Tower  
1660 West Second Street, Suite 850  
Cleveland, OH 44113-1412  
Phone: 216-522-2003 TTY: 216-522-8441

### Cincinnati Area Office

John W. Peck Federal Office Building  
550 Main Street, 10th Floor  
Cincinnati, OH 45202  
Phone: 513-684-2851 TTY: 513-684-2074

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## A Role Model

*Written by a Network Patient*

My husband and I were new to living with renal disease and dialysis. We joined AAKP and decided a trip to their annual meeting might help us by being able to talk with other families and healthcare professionals who understood what we were facing. Within an hour after checking in to the hotel, we sat down for lunch. As there was limited seating in the cafeteria, a woman who was alone asked if she could sit with us. Upon introducing ourselves we learned Mary (*not her real name*) was also a renal patient. This meeting with Mary changed our attitudes about renal disease and still impacts us today.

Mary was a highly educated professional who had achieved executive status doing international work for a large well-known corporation. She had traveled extensively and enjoyed living on a good income. Mary developed a form of kidney disease that made transplantation unsuccessful. She continued working on peritoneal dialysis at first, and then on hemodialysis after her peritoneum could no longer dialyze adequately. Mary struggled with the demands of an eighty hours per week executive job and hours required for hemodialysis. Conflict between her supervisors' demands of time and healthcare needs resulted in a confrontation and job loss.

Mary's determination and positive outlook led her to re-invent her lifestyle and work. She sold her home and moved into the city. Determined to spend her life helping others, she teaches at a local college part-time and devotes hours to tutoring inner-city children. She shared with us the joys of her life and fulfillment she experiences in helping others. She continues to be a role model for me.

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## Looking For a New Dialysis Facility

The Centers for Medicare/Medicaid Services have created a special Web page to help dialysis patients locate facilities and learn more about their services. **Dialysis Facility Compare** ([www.medicare.gov/Dialysis/home.asp](http://www.medicare.gov/Dialysis/home.asp)) provides information such as:

### Facility Characteristics

- Facility address and phone number
- Initial date facility became Medicare certified
- Types of dialysis offered (in-center hemo or peritoneal dialysis)
- Facility ownership type (profit or nonprofit; corporate or independent)
- Whether dialysis shifts are offered after 5 pm
- Number of treatment stations

### Quality Measures

- Percentage of patients receiving "adequate" hemodialysis (Measure - Urea Reduction Ratio of 65% or greater)
- Percent of patients that have anemia under control (Measure - hematocrit of 33 or greater)
- Patient survival rates (Measure - expected patient survival rate compared it to the actual patient survival rate at the facility)

Dialysis Facility Compare also has educational information and links to help patients to understand the importance of each quality measure and characteristic.

If you do not own a computer, many libraries offer free computer and Internet access.

## Upcoming Meetings for Kidney Patients and Their Families

Two conferences geared towards kidney patients and their families are scheduled for this fall. One of them will be held in our Network's area. Both meetings are excellent opportunities for education, new resources, and a chance to socialize and network with other patients and families.

### American Association of Kidney Patients 2005 Annual Conference

"Quality First: Patients Driving Excellence" will be held on September 1-4 in Las Vegas, Nevada. For more information call 800-749-2257 or visit <http://www.aakp.org>

### Renal Support Network's 2nd Annual Conference

"Health, Happiness, and Hope" will be held on September 29 - October 1 in Chicago, Illinois.

For more information, call 818-543-0896 or visit [http://www.renalnetwork.org/index\\_natmeeting.html](http://www.renalnetwork.org/index_natmeeting.html) or send an email to [info@renalnetwork.org](mailto:info@renalnetwork.org). (You can also request The Renal Network send you a brochure by calling 800-456-6919).

## Life Options Resource:

### *Nutrition and Fluids for People on Dialysis*

Life Options announces a free print version of its successful, on-line Kidney School Module 9: *Nutrition and Fluids for People on Dialysis* (<http://www.KidneySchool.org>). The module is available as four, separate PDF file downloads, customized for the:

- Person on hemodialysis
- Diabetic person on hemodialysis
- Person on peritoneal dialysis
- Diabetic person on peritoneal dialysis

Each module also has a companion download—a sample, two-week menu with recipes. Topics covered include nutrition basics, getting the right amounts of key nutrients, vitamins, limiting fluids and dealing with thirst, using food value books, planning meals and eating out, tips for gaining and losing weight, and strategies for change.

To obtain a copy visit the Life Options website at <http://www.lifeoptions.org>, or call (800) 468-7777, or email [lifeoptions@MEIresearch.org](mailto:lifeoptions@MEIresearch.org).

# RENAL OUTREACH

## Address Service Requested

### The Renal Network, Inc

911 E. 86th Street, Suite 202  
Indianapolis, IN 46240  
Phone: 317-257-8265  
Patient line: 800-456-6919

**Jay Wish, M.D.**, President

**Susan A. Stark**, Executive Director

**Kathi Niccum, Ed.D.**, Editor

Patient Services Director

**Patient Web site:** [www.kidneypatientnews.org](http://www.kidneypatientnews.org)

**Email:** [info@nw10.esrd.net](mailto:info@nw10.esrd.net)

Non Profit Org.  
U.S. Postage  
**PAID**  
Indianapolis, IN  
Permit No. 8606