



# RENAL OUTREACH

ESRD Networks 9/10

Summer 2002/Vol XIII, No. 2

## Robert Lee Felter

January, 1938 – March, 2002

*“This past March, the Network lost a mentor, leader and friend. Robert Lee Felter has been a voice for dialysis and transplant patients and a guiding force in much of what our Network has achieved. In life, Bob Felter’s courage, self-sacrifice and relentless devotion to patient care and quality of life, taught us all to value and celebrate the patient experience and point of view.”*

Such were the remarks of Dr. Jay Wish, Network Board President on the occasion of the unveiling of **The Robert Felter Award** at the Annual Nephrology Conference held this past May in Chicago, IL. The award will seek to honor individual patients and units for their contribution to patient services and education.

Bob touched the hearts and the minds of patients and staff alike through his wisdom, good humor and knowledge. He will be missed.

Sons Russell and Christopher with wife Pat holding the Robert Felter Award plaque. At far right, Kathi Niccum, Director of Patient Services .

## A REMEMBRANCE

"I was grateful to be in Chicago to see this award presented in my husband's, Bob Felter's, memory. A few years ago I stood with Bob as he accepted the Dr. Hayes Davis Award.

I remembered then, as I do now, that day almost 30 years ago when we were home dialyzing and Bob said to me, 'I sense your concern but don't worry I'll be around for a while as I have a lot to accomplish.'

Bob's mission in life was to work on behalf of his fellow kidney patients.

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# *New opportunities for patients who want to work, learn*

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## **THE KIDNEY SCHOOL**

How can you live a long and full life on dialysis? By having a positive attitude, getting answers, and taking action to manage your own health.

The Kidney School is an interactive, web-based learning program. It was designed to help people learn what they need to know to understand kidney disease and its treatment, adjust to kidney disease, make good medical choices, and live as fully as possible.

The Kidney School currently has seven (7) modules to choose from: coping with kidney failure, what kidneys do and what happens when they fail, treatment options, lab tests, working with your team, anemia, and following your treatment plan. You decide which modules to visit and when—so what you learn is entirely up to you.

If you are already using the Internet, getting to Kidney School is easy. If you don't have a computer at home, at work, or at dialysis, most public libraries offer free Internet access and have staff to help you. Visit the Kidney School on the WEB at [www.kidneyschool.org](http://www.kidneyschool.org). It's free and it's open 24 hours a day.

Kidney School is offered by the Life Options Rehabilitation Program, which has been doing research and offering research-based educational resources for kidney patients since 1993. For free

educational materials visit the Life Options website, [www.lifeoptions.org](http://www.lifeoptions.org), or call (800) 468-7777. Life Options is supported by Amgen Renal Advances and administered by the Medical Education Institute of Madison, Wisconsin.

## **TICKET TO WORK PROGRAM**

The Ticket to Work Act was passed on December 17, 1999. The program is designed to give people, between the ages of 18 and 65, who receive Social Security disability benefits an opportunity to find steady, long-term employment. The program will be phased in nationally and is expected to be operating in the entire country by January 1, 2004.

Of the four states covered by The Renal Network only Illinois is currently participating in the program. Illinois was one of 13 States playing a part in the first phase of program implementation begun in February 2002.

In the latter part of 2002, the program will be expanded to an additional 20 States — among them Indiana and Kentucky. The third phase, to be put into operation in 2003, will open up the program to the remaining 17 States — bringing in Ohio. Eligible adults will be identified and issued tickets, which they can use at participating Employment Networks to obtain training, employment services or a job.

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## *a new skill or find out more about kidney disease...*

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Participants will also be eligible to receive other services such as benefits planning. What makes this program different is that participants will be able to keep more of their healthcare coverage for a longer period of time while working.

Social Security Administration has contracted with **MAXIMUS, Inc.** to help manage the program. Interested persons can get information about the Ticket to Work Program by calling **MAXIMUS, Inc.** at their toll-free numbers, 1-866-968-7842 or 1-866-833-2967 TTY or by logging on to [www.yourtickettowork.com](http://www.yourtickettowork.com). The Ticket to Work Program is voluntary but for many patients, this may be the first feasible means of returning to work.

## **VOCATIONAL REHABILITATION**

Each state has established vocational rehabilitation agencies to help individuals with disabilities find employment, arrange training in new job skills, and assist in job placement. For more information on vocational rehabilitation services available in the Network 9/10 area, contact the agency in your state.

### **Illinois**

#### **Department of Rehabilitation Services**

100 W. Randolph  
Chicago, IL 60601  
312-814-2934  
800-843-6154

#### **Department of Rehabilitation Services**

623 E. Adams Street  
P.O. Box 19429  
Springfield, IL 62794-9429  
217-782-2093  
800-252-8635

### **Indiana**

#### **Division of Vocational Rehabilitation Services**

Indiana Government Center  
402 W. Washington Street, Room W453  
P.O. Box 7083  
Indianapolis, IN 46207-7083  
317-232-1319  
800-545-7763 ext. 1319

### **Kentucky**

#### **Department of Vocational Rehabilitation**

209 St. Claire Street  
Frankfort, KY 40601  
502-564-4440  
800-372-7172

### **Ohio**

#### **Rehabilitation Services Commission**

400 E. Campus View Blvd.  
Columbus, OH 43235-4604  
614-438-1210  
800-282-4536

**LET US IN ON ....  
*THE SECRET!***

Does your unit have a unique way of promoting positive patient—staff communication?

Please share it with us, so we can share it with others.

Send a brief description of what you do, who all is involved and how it gets folks talking.

Mail it to:

The PLC Special Projects  
The Renal Network, Inc.  
911 E. 86th St.,  
Suite 202  
Indianapolis, IN 46240

**HERE - WE'LL SHARE ONE OF OUR'S ...**

***Making Birthdays a Special Occasion.***

***What we do ...***

1. Appoint a patient or staff member (or have a team of one patient and staff) to keep a current birthday list of patients and staff.
2. Obtain birthday banners or balloons to place within patient's treatment or staff work areas.
3. Purchase special birthday hats that the birthday persons may wear. This can be as simple as the traditional paper cone hat or as fancy as a crown.
4. Publish an announcement of birthdays regularly — in the facility newsletter, on the bulletin board or in the treatment areas.
5. Be mindful that any plans you make are in keeping with individual wishes. Religious beliefs or cultural differences may limit an individual's ability to participate. Also be aware of recent events in a person's life which may make them less receptive to a birthday celebration.

***How it works ...***

1. Everyone gets a chance to be the center of attention and receive birthday greetings. It's recognition, as well as, a morale booster.
2. It gives everyone an opportunity to talk to folks that they would not usually connect with at the unit.
3. It gets patients and staff interacting on a fun and positive note.

***Enjoy and make the most of the celebration!***

## FOR COUPLES ONLY

Researchers at Boston College are launching a new study focused on patients with End Stage Renal Disease (ESRD) and their spouses.

Why a special study?

Kidney patients are faced with tough choices every day. Decisions are made, by and large, with the help of a wife or husband. Yet most of what we know about the effects these decisions have on day-to-day family life typically comes from the kidney patient.

Obviously they affect the spouse as well. Yet little is known regarding the spouse's role in decision-making and the effects of certain decisions on their lives.

This study hopes to shed some light on these issues. The researchers are seeking 300 couples to volunteer to join the study.

To be eligible, both partners must agree to participate. Patients must be 55 or older and on hemodialysis for at least six months. Couples must be married or living with their partner for five years or more.

For couples in our Network, the study involves only phone interviews.

To learn more about the study, please call Jennifer Rosenbaum toll-free at 1-866-772-3387.

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## A REMEMBRANCE (cont'd)

At Bob's funeral, Martinlow Spaulding stressed in his tribute that, 'Bob was the *Man With The Plan.*'

I don't believe that Bob thought he was finished with his plan after I saw how filled his monthly planner was. I guess someone else had a plan for Bob.

And now we must trust that others will be called on to carry on with '*The Plan*' because in some ways it belongs to us all.

I thank everyone involved for this special honor in Bob's Memory --- God Bless," Pat Felter.

## CARRY ON

### A Tribute to Bob Felter

*(an excerpt from a poem by  
Martinlow V. Spaulding  
delivered as part of Bob's eulogy)*

Accept the challenge  
Learn - life's lessons  
Reach out - for a hand  
And carry on, carry on my friend  
Send a message -  
with your faith and conviction.

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# FAMILY AFFAIRS

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(This is the first in an on-going series of articles, created by the Family Sub-committee of The Patient Leadership Committee, focusing on living with chronic kidney disease from the family/caregiver's point of view. Your comments and contributions are welcome.)

## ***What About Us — The Family*** Sonia Juhasz

In a previous Renal Outreach (Winter, 2002), there was an article about family stress along with the results of a recent survey on the same issue.

In both of these articles it stated that "dealing with kidney failure is a family affair" and that most families feel alone and unsupported.

I can attest to all of that for my daughter has renal disease. I am not only a mother but also a nurse. Not that that should make a difference — but to most people including me, it made a big difference.

As the story begins, my daughter was diagnosed with renal disease at the age of seventeen to the shock of everyone including myself. It was at that point that my life began to change --- some for the good and some for the bad.

For two years she was controlled with medication. No one thought a whole lot about it except me. To my daughter, I became the ultimate nag and basically alienated her from me.

By focusing on my daughter, I often overlooked my son's needs. Eventually he began to experience bouts of anger against me.

It wasn't until my daughter's kidneys began to fail that reality set in for everyone. It was at that point that things began to spiral down for me.

The feeling of "being alone" descended on me like a cloak. As did all of the tormenting questions like, "What had I done wrong as a mother? And, How can I fix this; can I fix this?" And then there was the anger.

My extended family was not very supportive. Their thinking ran along these lines: "If we don't see them, then we don't have to deal with it." Mainly, what they wanted to know was if their children could catch this or not. There was no — "How can we help?" or, "What can we do for you?"

Some of the relatives took the opportunity to bring out some old sore points like, "If you would have just stayed home and not worked then none of this would have happened."

Logically it made no sense but of course it made me feel guiltier.

To make matters worse, I would argue with my husband for not supporting me but in actuality he didn't

know how to help. Meanwhile, my son just became more distant.

It was one weekend after a typically bad week — her starting dialysis, arguing with my husband, no support from my family, my son being mad at me, and my daughter looking sicker than I had ever seen her before — that I thought about just giving up.

I went to meet one of my friends. I began talking to her about my fears and feelings of being alone. She suggested that I talk with someone, saying “If you can’t get yourself together than you can’t help anyone including your daughter and family that need you.”

It was at that point that I went to speak to a psychologist who sat and listened, who helped me understand it was not my fault and who helped me identify and redirect my anger so that I could do — what I could and needed to do. Talking things through helped me get myself together. Things aren’t perfect but they are more manageable.

I know that I am not the only person feeling this way. I want you to know that you are not alone. It’s not your fault. We all have our ups and downs. When you feel like “you’re going down for the count” talk to someone.

For support, all we need is to **STAND TOGETHER!**

## SYMPTOMS OF DEPRESSION

Newly diagnosed patients and their family members often experience a sense of sadness and loss. These feelings may be a part of a normal grief reaction.

During this period, the patient or family member may feel unable to cope with life in general. Gradually, the reality of kidney failure is accepted. The feelings of sadness begin to lift.

At this point, patients and family members are able to learn how to adjust and adapt successfully to the changes brought about by kidney failure. If, however, grief and loss give way to a real sense of despair which lasts for some time, a professional consultation may be needed.

Depression can happen to anyone at any time. It’s important to know some of the general symptoms.

The following list provides some of the major warning signs. Experiencing four or more of these symptoms for over a two week period may mean it’s time to ask for help. Some of these symptoms could also be typical of kidney disease, so it may take a medical professional to help sort it all out.

Keep this list handy and review it from time to time.

# SYMPTOMS OF DEPRESSION

## *A simple checklist of symptoms:\**

- A persistent sad, anxious or “empty” mood
- Loss of interest or pleasure in ordinary activities, including sex
- Decreased energy, fatigue, feeling “slowed down”
- Sleep problems (insomnia, oversleeping, early-morning waking)
- Eating problems (loss of appetite or weight, weight gain)
- Difficulty concentrating, remembering, or making decisions
- Feelings of hopelessness or pessimism
- Feelings of guilt, worthlessness, or helplessness
- Thoughts of death or suicide; a suicide attempt
- Irritability
- Excessive crying
- Recurring aches and pains that don’t respond to treatment

\* adapted from the National Institute for Mental Health literature

## *For More Information on Depression:*

- National Mental Health Association  
(800) 969-NMHA,  
<http://www.nmha.org/>
- National Depressive and Manic Depressive Association  
(800) 826-3632  
<http://www.ndmda.org/>
- National Kidney Foundation  
(800) 622-9010  
<http://www.nkf.org>

## **Are you moving or have you recently moved?**

Please let us know of any permanent change of address. Clip the mailer portion of the newsletter below and together with your new address mail to: Renal Outreach, The Renal Network, 911 E. 86th Street, Suite 202, Indianapolis, IN 46240.

# RENAL OUTREACH

**The Renal Network, Inc.**  
911 E. 86th St., Suite 202  
Indianapolis, IN 46240

***Address Service Requested***

**Jay Wish, M.D.,** *President*  
**Susan A. Stark,** *Executive Director*  
**Kathi Niccum, Ed.D.,** *Editor*  
*Patient Services Director*

**Patient Line: 1-800-456-6919**

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

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