



RENAL OUTREACH

ESRD Network 9/10

Summer 2003/Vol XIV, No.1

Patient Leadership Committee Family Focus Series

Robert Felter Memorial Award

The Renal Network, Inc. is pleased to announce the recipients of the 2003 Robert Felter Memorial Award.

Receiving the patient award this year is Kathy Kirk-Franklin of East Cleveland, OH.

Ms. Kirk-Franklin has been an active member of the Patient Leadership Committee for the past three years. She has worked on issues related to compliance and patient/staff communication.

Ms. Kirk-Franklin is a frequent contributor to her local facility newsletter. She also has served as an advocate for patients on issues such as technician certification and kidney disease awareness and early recognition.

Continued on page 7

Role Reversal

By Guy Tibbels

(Pictured on right is Guy and Rose Tibbels with son, Guy II "Tug" and daughter, Annie.)

What is role reversal? In a family, what does it mean? Is there really men's work – women's work? Should the man always be the main breadwinner of the family? In today's world does it really matter?

I can't answer these questions for you individually. Everyone has their own perceptions about how they want to live their lives.

But when you and your family face a challenge like kidney failure involving daily dialysis, fistulas, catheters, and transplants - family roles start to change. Chronic illness affects how you live your daily lives and how you must look at your future.

Currently, in our family, my wife Rose has the full-time job, as an elementary school guidance counselor. That is the job with the benefits.

Myself, due to a few challenges (diabetes for 20 years, kidney failure and 2 transplants), I've had to steer away from full-time jobs.



Continued on page 2

Role Reversal - cont'd

During the summer months I own and operate a daily charter fishing business and help manage our family-owned marina. I coach football in the fall and substitute teach during the winter.

I maintain an active schedule, but one that I can mix and match according to meet my needs.

As a family, we've reached a balance that works for us. But there were a few bumps in the road along the way.

In the beginning, it was just Rose and myself. The first six years of my kidney pancreas transplant went smoothly. So the role reversal thing was present but not really prominent.

But then the transplanted kidney failed and the daily challenges increased.

It was back to frequent doctor visits, to taking more medication, to going on dialysis, to getting on the transplant waiting list, to getting retransplanted and to going through recovery one more time.

At the same time Rose now faced some challenges of her own - a one year old in diapers and another one on the way, her regular full-time job, and taking care of me. Actually, she had to take over all of the family roles in one capacity or another. Talk about a triple whammy!

After a while, coping with this type of situation can eat away at a person by tearing away at the family's image and self-worth. IF YOU LET IT!

If role-reversal is something that bothers you whether male or female, patient or caregiver, family member or friend - what

Again, I can't give you an answer. You have to find what best suits you, your family and your situation.

But I can offer some pointers, ideas and ways of looking at things that helped my family take control of what could have been a very negative situation.

When tackling role reversal, keep in mind some of the following:

- 1) Be realistic - learn to accept things as they are and deal with it in a positive manner;
- 2) Give it your best - accept only your best effort and never be satisfied with mediocre attempts;
- 3) Be grateful for what you have - always look at your glass as being ½ full and never as ½ empty;
- 4) Talk it out - when feeling down, talk to someone who understands and when it's all out, let it go and get right back on track;
- 5) Set goals - for yourself and as a family; write them down, discuss them, check them off as you achieve them, review and change them as needed;
- 6) Use common sense when making decisions - don't plan a ten-hour day because that's what you are *used to doing* when your energy level allows for only a four-hour work day along with a required nap;
- 7) Accept help - learn to let others, especially family, give you a helping hand no matter how small; it gives them a sense of involvement and helps reduce their feelings of helplessness;

8) Evaluate yourself - make sure you're not taking the easy way out by say, "I can't do this because I'm sick;" don't be a whiner or carry a chip on your shoulder; check it out and see if that's a defense, your way of coping with fear and anger;

9) Be a good listener – others who share in your care (caregivers) especially need to express and share their thoughts and feelings with someone – particularly you.

10) Be a team player - work hand-in-hand with caregivers, doctors and nurses; it's important to make your needs known and to express your point of view but it's equally important to listen, take in a different perspective and trust.

11) Maintain a positive attitude, it's the key to success when dealing with kidney disease or any other challenge that may confront you or your family. Attitude affects the way you think, feel and act. So watch what you say – use *challenges* instead of *disease* and *illness* and say, "It's a slow day" instead of "It's a bad day."

12) Be mindful of who you are – role reversal may mean that you are no longer the primary breadwinner or main caregiver but it doesn't mean that you lose your place in the family. You are still the father or mother; you are still a husband or wife. Your role and your identity are not the same thing.

Hopefully these ideas will be useful to you. Refer to them. Try them. Work on solutions. Role reversal may present a challenge to the family. But the more

you talk things through and keep an open mind, the less stress will be felt by you, your family and friends.

Learn to look at every challenge as an opportunity to grow as a family. It will help you cope not only with role reversal but with any other obstacles you and your family may face.

Mother Reflects on Family's Struggles

By Desy Burdette, Former Member of the Patient Leadership Committee

Whenever I reflect on the spring of '91, I think of a vast ocean with nothing in sight except a person in the distance whose arms are flailing wildly in a futile attempt to avoid drowning. That person was me.

It all started when my two-year -old son, Frankie, developed what seemed to be a cold. I took him to our family doctor who put him on antibiotics. When he finished the medicine, the cold symptoms had diminished; but he had become extremely lethargic.

With my mother's urging, I took Frankie to a local hospital emergency room. At first, they also thought his symptoms were the result of a cold. Then, again at my mother's insistence, the doctor ordered a blood test. When the results came back, the test was run again.

The doctor told me Frankie was either extremely dehydrated, or there was a problem with his kidneys. I was devastated.

Where's Your Get Up And Go?

By Jeannette A. Cain, B.S.R.N., M.S.M., C.P.H.Q.

Spring is here and summer is not too far behind. Don't let lack of energy and fatigue spoil your fun.

Lack of energy and chronic fatigue can occur for a variety of reasons when you have kidney disease.

Toxins accumulating in your system; fluid overload putting stress on your heart; a lack of erythropoietin caused by anemia; as well as, a lack of exercise can all result in a reduced energy level.

Other medical conditions can cause fatigue. Depression also lowers your energy. Depression can also lessen your motivation to make the changes needed to regain your stamina and zest for life.

Fortunately there are a number of things that you can do to make sure that you are getting the most out of life.

First of all, talk to your doctor and healthcare team.

Discuss the symptoms you are having. Be specific and give examples. Your doctor and healthcare team might be able to prescribe changes in your treatment or medications that will help you cope with the underlying problems.

Second, know your blood laboratory numbers and what they mean.

Your numbers reflect your dialysis treatment's capability of cleansing your blood, your fluid balance, as well as determine if you are anemic.

Compare your treatment outcomes to your diet, fluid intake and activities on a

regular basis. This will help you to understand what does or does not help you feel better.

Third, remember that it's an ongoing learning process.

Our bodies change (whether we have kidney disease or not) and along with our physical changes what we can and cannot do.

Be flexible and accepting of change. Be willing to adapt to your current circumstances and take each day as it comes.

- Learn to conserve your energy. A good night's sleep, plenty of rest and naps give your body time to slow down and help to restore energy.
- Learn to pace yourself. Slow down, take breaks and give yourself extra time when planning activities.
- Learn how to re-charge yourself. Find time to relax and do something that you enjoy. Light exercise also helps to create energy. Take short walks or do some simple stretching exercises.
- Learn to say, "No." Don't take on more than you can reasonably do. Aside from wearing you out physically, it increases stress and anxiety.
- Learn to ask for help. Don't shy away from asking family and friends to help you with errands and household chores.

Where's Your Get Up And Go? cont'd

- Learn to eat a well-balanced diet with high quality proteins and keep adequately hydrated. Ask advice from your dietitian as you plan your diet.

It is possible to increase your energy especially when you take charge and work together with your healthcare team and family.

Educational Resource Update

The Life Options Rehabilitation Program (LORAC) has updated its patient guide on employment options.

Employment: A Kidney Patient's Guide to Working and Paying for Treatment now has information for people with kidney disease and people on dialysis or with transplants.

Topics include employment and vocational rehabilitation; Medicare, Medicaid, and health insurance; disability programs, including SSDI and SSI; and federal legislation affecting kidney patients.

The booklet also includes a glossary of terms and a list of resources.

Visit the Life Options Web site at www.lifeoptions.org to download a copy of the booklet.

You can also obtain a copy by writing Life Options / Rehabilitation Resource Center c/o Medical Education Institute, Inc. 414 D'Onofrio Drive, Suite 200 Madison, WI 53719 or by calling (800) 468-7777.

The Centers for Medicare and Medicaid Services (CMS) has updated its Medicare publication,

Preparing for Emergencies: A Guide for People on Dialysis.

This booklet offers invaluable information on how to manage during emergency situations that make it impossible for patients to obtain dialysis. It contains many helpful hints on how to prepare, for example, what foods and supplies to have on hand and how to disinfect water.

To obtain a copy ask your dialysis social worker or visit the Medicare Web site at www.medicare.gov and click on the publications link.

You can also call Medicare at 1-800-MEDICARE and ask for Publication Number 10150.

Visit The Renal Network patient Web site (www.kidneypatientnews.org) to find these and other educational resources and links.

I then tried to console myself by thinking, "It's probably not that bad."

Frankie was transferred to Riley Children's Hospital in Indianapolis. He was initially diagnosed with hemolytic uremic syndrome and put on hourly peritoneal dialysis in Riley's ICU immediately.

I tried to comfort myself with the thought that, according to the doctor, HUS is almost always a temporary condition.

I'll never forget the moment Frankie's pediatric nephrologist gave me the result of my baby's kidney biopsy. The doctor informed me that the biopsy indicated old scar tissue on Frankie's nephrons.

My baby's kidney failure was permanent. He had end-stage renal disease.

As soon as the doctor left, I sought refuge in the closest private room I could find, so that I could cry my eyes out.

When I returned to Frankie's room, I found my nine-year-old daughter, Nicole, calmly reading a book to her brother. She chose to be strong and do the most positive thing she could have done for both her mother and brother at the time.

But we were destined to face more obstacles. First, my HMO offered to provide a nurse so that I could finish my work as a high school English teacher. However, the HMO decided to renege on its offer on the recommendation of a social worker who felt I should quit my job and stay home to care for Frankie.

Although my mother-in-law offered to learn how to administer peritoneal dialysis

so she could take Frankie to her home in Dallas, the HMO vetoed it. They would not provide insurance coverage for out-of-state care.

My husband and I learned how to perform the home peritoneal dialysis exchanges that Frankie required four times a day. During the summer of 1991, Frankie received a kidney transplant from his father. It failed within a week.

Soon after that my marriage failed as well. Sadly, since that time, Frankie's father has chosen to see his son only on an extremely infrequent basis. His paternal grandparents, however, have maintained a close relationship with him despite the fact that they live so far away.

In May of '92, Frankie got a cadaver transplant right after his fourth birthday. This time it failed within 12 hours. A year and a half later, Frankie was diagnosed with ESRD. I was then told I would have to administer Epogen injections to him three times a week to combat anemia. He could not get accustomed to his shots. He would scream in agony.

Eventually, he learned to tacitly comply. He and I agreed that I should give him the injection while he was asleep; since he wouldn't see it coming, he would not have an opportunity to tense up in anticipation to what was about to happen. Regardless, it still hurt me to know that he was suffering because of what I had to do to him.

It has been about 12 years now since the spring of '91. Frankie is almost 15 years old.

Mother Reflects on Family's Struggles - cont'd

After over eleven years on peritoneal dialysis, he finally received a kidney transplant that worked in October 2002.

After all this time, he is still in the "normal range" on the growth chart. The renal professionals have led me to believe that that is remarkable. He is a happy, gregarious, and active child. He looks like a picture of health despite a slender physique.

After years of having a tube hanging from his abdomen for dialysis, it was recently removed since he is producing urine. I have to smile every time I hear him go to the bathroom. Before 1991, I never would have thought the sound of urine pouring into a toilet could be so wonderful.

My daughter Nikki has been my rock. When she was in elementary school, she did a science fair project on peritoneal dialysis. A few months later she insisted that she should learn how to do the dialysis, so she could help me. She felt that Frankie's ESRD was a family issue to be handled by the entire family.

I had to be conscious of making sure she enjoyed being a child.

She has grown and matured into a responsible, scholarly, outgoing, popular, charismatic and happy young adult. Currently, Nikki is a junior at Ball State University. She just won, despite tough national competition, a prestigious internship with Pfizer Pharmaceuticals.

She intends to be a pharmaceutical representative when she graduates. Needless to say, I'm very proud of her.

As for me, I joined the Patient Leadership Committee of The Renal Network. I hoped I could be of help to others who may be forced to travel a similar road. It was very rewarding working with others who have a connection to ESRD. As a result of my committee work, I even met some absolutely wonderful social workers!

I also learned to find humor in life. I seek activities that bring me joy and make me laugh. My children and I believe we have a very "functional family."

Eventually, I realized I no longer see myself as that desperate woman trying to stay above water. Now I envision myself swimming in an ocean towards a not too distant shore. Standing there on the beach, I can see Frankie as a grown man beckoning me to come ashore.

Robert Felter Memorial Award cont'd

Receiving the facility award is the Centers for Dialysis Care of Euclid for their innovative art therapy project entitled, "A Day in the Life of a Dialysis Patient." Barbara Greenwood, art therapist, will be helping patients explore their thoughts, emotions and feelings by creating photographic journals of one day in their lives.

The resulting art exhibit will serve to educate local communities about people on dialysis and will be used to highlight the use of art therapy to promote healing and wellness in patients.

Have a problem or a complaint related to your treatment? Here are some things you can do —

1. Speak to your health care team. Let them know exactly what is not working for you. Be specific and give examples. Discuss possible solutions. Give issues enough time to be worked out. Make a *good-faith* effort to resolve the problem.
2. 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. Make sure that you follow all of the steps outlined.
3. Still have questions? The Renal Network is available to help you and the staff involved arrive at a workable solution. Sometimes the problem can be handled informally through discussion, negotiation or education. Some issues are more serious in nature. In such cases, a formal grievance can be started and an investigative process will be carried out to explore the issue. The Network's Medical Review Board reviews all grievances.
4. Some issues are under the authority of another agency, such as, the State Department of Health. The Network will help you to determine the most appropriate agency to review your concern.

Ask your social worker for a copy of The Renal Network's *Grievance Process*. Or visit our patient Web site, *Kidney Patient News* (www.kidneypatientnews.org), for more information. Or, you can call the Network office and ask that a *Grievance Packet* be mailed to you.

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
Email: info@nw10.esrd.net

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