



# KIDNEY CONCERNS

SPRING/APRIL

ISSUE 32

## A FAMILY'S VIEW

Kidney Concerns received a letter last year asking for an article about how family members of ESRD patients adjust and cope with this disease when a loved one is diagnosed. Hurlin Lee Wilson and Tina Lindsay, father and sister of PAC member Carolyn Wilson Davis have submitted the following article. We encourage other family members to submit responses to Network 13 on how they have adjusted and coped.

**Hurlin Lee Wilson:** Renal failure made itself known to my family when my daughter was diagnosed with the disease. My life, our lives, have had its share of peaks and valleys since. My deepest valley began when my daughter asked me if I would consider being an organ donor for her. I had not realized that her condition was that serious. There was no thought process involved in my decision, the answer was yes. A peak in this process was when we were informed that we had the best percentage of match for the transplant that the facility had ever tested. This provided optimism and happiness that a good outcome was possible with this prognosis as we prepared for the transplant. The day of the operation filled me with excitement and promise, to be able to do this for my daughter whom I love so much, was very special. I was the happiest man in the world. We slipped into the valley the next day when it became obvious that my daughter's body was rejecting the kidney. I was simply devastated. The hurt, anger and frustration were almost too much to endure. All I could think about was my daughter and what I could do now. Seeing the hurt and disappointment in my daughter's eyes was the most painful situation I have ever had to deal with. I even asked the doctors to use my other kidney, as death appeared better than watching the hurt in my daughter's eyes.

It was difficult to participate with my daughter when she started hemodialysis. She did not tolerate it well and her access had continuous problems. She had many revisions done to her access. I worried if she was strong enough to endure any more surgeries. Although I was very concerned I could not let my daughter see the concern and fear that felt overpowering to me. I stood by her side and assured her that everything was going to be all right. Hope presented itself when we were introduced to peritoneal dialysis, an in-home dialysis treatment. My thought was simple, maybe no more surgeries for my daughter. She did need an access placed for peritoneal dialysis but the need for revisions did not occur with this type treatment. We attended class together to learn the process of peritoneal dialysis. I began to see that if my daughter followed the directions and requirements of peritoneal dialysis there was hope, a new lease on life. I can say that peritoneal dialysis provided that for my daughter. She has had several bouts of peritonitis but has recovered well from them. Yes I am still fearful everyday but as I watch my daughter going to work, raising her son, singing in the church choir and trying to improve her life I simply thank God and ask his continuous blessings and to watch over her from day to day. I realize there will be more peaks and valleys but I thank God for my daughter.

**Tina Lindsay:** If I said I fully understand what my sister feels both emotionally or physically I would not be being honest. The truth is that my older sister has always been independent, the "I got it under control" type women. She was always involved in organizational activities. (Continued page 3)

# "Glad You Asked That . . ."

**QUESTION:** Why do I feel thirsty and what can I do about it?

**ANSWER:** *NEVER SAY THIRST, SAY DRY MOUTH!!*

Dialysis patients frequently complain about being thirsty. This is what makes some of them want to chew on ice and drink so much water, which also accounts for all those extra pounds between dialysis treatments. Try as they may, some patients feel like they will never quench their thirst. That's the point: they won't. Because it is not thirst.

What you feel is actually a dialysis dry mouth. As a matter of fact, real thirst among dialysis patients is rare! Suppose you and I are both "thirsty." I have working kidneys so this means I have just been exercising strenuously. I am covered in perspiration and my mouth is bone dry. You, because your kidneys do not work, feel that way most of the time except you are not covered in perspiration. So we both drink a couple of tall glasses of water.

Fifteen minutes later you have that feeling again, but I do not. This is because my thirst was real thirst, which can be quenched. What you feel is dry mouth, which cannot. So you drink another glass of water. Thirty minutes later you still have that feeling and I am still satisfied. No matter how much water you drink, that feeling will not go away.

So, could it be real thirst that you are feeling? Maybe not. In fact, if you look at it from the point of view of your lungs and internal organs, your body may be closer to DROWNING than being thirsty.

Certainly you do not feel like you are drowning. You feel more like you are dehydrating. I assure you, although you may feel dehydrated, about the only time most dialysis patients come close to dehydrating is toward the end of their dialysis treatment. For certain, not a day or two afterwards! You may even look dehydrated, but you're not.

I recall a patient who went to the emergency room with nausea and shortness of breath. The emergency room physician swore he was dehydrated and ordered him to drink as much ice water as he could hold. [No, he never told the doctor he was on dialysis.] The patient knew he had at last found the doctor he had been looking for! A man who said drink all you want! It took three treatments in three days to get all the fluids off of him.

Maybe you could change your mind about thirst. You rarely experience genuine thirst. I know it feels like thirst, but it is dialysis dry mouth. And dry mouth does not require you to swallow water. With this in mind, it is easier to use all those tricks the dietitian taught you like brushing your teeth, eating an apple, chewing gum, breath mints, etc. Or you can swish some water around your mouth and (pardon) spit. It may be hard at first, but you can learn to have water in your mouth and not swallow. And remember, stop thinking thirst. Think dry mouth!

Network 13 thanks Ramiro Valdez of Network 14 for permission to use this article.

*If you have any questions for "Glad You Asked That", forward them to ESRD Network 13, 6600 N. Meridian, Suite 155, Oklahoma City, OK 73116-1411, or phone (800) 472-8664. Selected questions will appear in future issues of Kidney Concerns.*

## **FILL OUT YOUR CENSUS**

It is important to complete your census form. The information you provide helps determine how Federal funds are allocated, including money for health programs, transportation and other programs. Take the time to complete it now.

## ORGAN DONATION

Organ Donation could well be considered the first step in the process of transplantation. Organ Donation and Transplantation seem to be appearing in the news more and more lately. In fact, are you aware that National Organ and Tissue Donor Awareness Week is in April! Despite the increased attention, there are thousands of patients still waiting and we still lose too many because an organ cannot be found in time. Some of us are experiencing this shortage everyday in our own lives. Others have watched friends and fellow dialysis patients wait and wait only to watch them lose the battle due to this shortage. As we know the organ shortage is real and deadly serious.

I know we are preaching to the choir but we as ESRD patients, of all people, understand how critical it is that the organ supply increases. Those of us on dialysis and waiting for a kidney transplant have a personal stake in this issue and an opportunity to be a credible spokesperson to promote donation. Those of us who are alive and well because of another's selfless act of donation have a special obligation and responsibility to become living testimonies to the miracle of transplantation.

But how? The answers will vary as widely as the people who will ask the question. Some of us work in the news media and the answer is obvious. Others, by virtue of their jobs or positions, may find themselves asked to be interviewed. For most of us, however, the answer may not be so clear. In my case, I asked to make a presentation to my company at one of our company wide meetings. I also made sure that my co-workers, who could see how well I responded to a transplant, were aware of the issues. As I met new people and found myself in new groups I would tell my story. I was proud to be the owner of a new kidney and I let that be known. I tried to pick the opportunities carefully and I was always brief, direct and straight to the point of donation. You may not want to call attention to yourself but you will find that people are truly interested in our stories and that becomes the perfect opportunity to explain how donation has and will make an incredible difference in your life. If you're not comfortable in speaking about it, then encourage your family and friends to tell your story when they have the opportunity. My daughter spoke about organ donation on her college campus.

Now that you have their attention, what do you say? The message is simple and powerful: Be an Organ Donor by Signing an Organ Donor Card AND TELL YOUR FAMILY. Donors must make their decision known to their friends and family so their wishes will be carried out after death. Donations will not happen unless your loved ones make it happen. While this does indeed aggravate the organ shortage, it is a fact and cannot be ignored.

This is the single most important message. You can get further information on the web at UNOS, [www.unos.org](http://www.unos.org), or Transweb, [www.transweb.org](http://www.transweb.org), or call 1-800-355-SHAR(E)(7427).

Article submitted by: David Broach, PAC Member

### **A Family View (continued)**

The renal failure she has just seemed to show its ugly head out of nowhere. When it did, the changes she would encounter over the years appeared to be overwhelming. Overwhelming to the point that I think I have been in denial. I have actually caught myself getting upset about her emotional rollercoasters and her need to decrease her physical activities. All I could think is "shame on you Tina for not being more understanding or empathetic", but I wanted my older sister the way she used to be and this was not fair.

As the years pass on I watch this remarkable woman, my sister, continue to strive to reach higher heights and her "Duracell" battery energy keeps her ticking even longer than me. I am amazed and wonder if I could be that courageous. I have come to realize that life takes us through many changes. Some changes help us to grow, help us to love and help us to be humble ourselves to realize who is really in control. My desire is to learn more, be available whenever one of the emotional rollercoasters comes again and my sister needs a shoulder to lean on, cry on and steady herself. I want to be understanding when she does not feel up to an activity and to offer ringside seating whenever possible.

Sister, please know that even when it is not spoken as often as it should that your baby sister loves you, that your life is full of abilities to do all things through Christ that strengthens you.

## Taking Charge of Your Healthcare

Here are some tips to learn more about taking care of yourself. These will help you make better decisions about your future healthcare.

Use available resources - Learn as much as you can about your condition. Ask questions of your health providers, utilize the web, go to the library, contact agencies that provide educational material at low or no cost. The more knowledge you have about your condition, the better decisions you can make about your treatment.

Keep records - Keep notes and records about immunizations and tests with results in a notebook, in a computer spreadsheet (that you can print when needed) or on a card so this information is readily available for you and your healthcare providers. You may also want to note when immunizations and tests are needed. It is very important for dialysis patients to keep track of lab values and their URR or Kt/V to ensure they are getting adequate dialysis. You also want to have a copy of your medical records to be available as needed.

Ask questions of your healthcare providers - Remember that these people work for you. If they are busy ask when a good time is to discuss your concerns with them. Make a list of the questions you need answered so you will be prepared for your visit. Get the information you need to understand, this will decrease feeling anxious.

Know which medication/drugs you are taking - Always ask your healthcare professional what medications they are prescribing for you and how to use it correctly. Ask about side effects and what you should do if you experience them. Make a list and keep it with you on all the medications that you are on. Let the doctor, dentist and pharmacist know the medications on the list so you can avoid any dangerous drug interactions. Be sure you get the right prescription. Do not change doses or share medications with others.

Get tested - Know what tests you should have, such as TB, hepatitis A&B, or immunizations, such as tetanus, pneumonia,MMR.

Have regular check-ups- Ask your healthcare professional about how often you should get a general physical examinations, if you need to see a specialist and how often, and treatments that you need for any condition. For dialysis patients you need to know how many days and for how long each dialysis sessions should be.

Exercise and proper diet- Exercise regularly, this improves the overall condition of your body, eat right, talk with a nutritionist if you have special dietary needs, and wash your hands often to prevent the spread of disease.

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### WE SAY GOODBYE

At the start of the new millennium the angels rejoiced as they were joined by one of their own. They met and guided this friend to heaven to his rightful spot. Those same angels will wrap us in their wings as we struggle with the loss of our friend and dry our tears with the tips of their wings. O. Walter Morant, "The Maytag Man" and dedicated member of the Network 13 Patient Advisory Committee, joined the Lord on January 3, 2000. His wisdom and contribution will be missed by all in the renal community. Our comfort comes from knowing you are in peace. Our thoughts and prayers are with his wife Sandi, who was always at his side and taught us all what love and commitment are. She exemplified for others what family involvement meant. May the memories of Walter sustain and bring a smile back to her life as she begins her new journey. We at the Network will pass on the wisdom we were privileged to receive from you.

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*Kidney Concerns* is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for SUMMER/JULY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

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This newsletter is developed while under contract with the Health Care Financing Administration, Baltimore, Maryland. HCFA Contract #500-97-E031.