

ESRD NETWORK 136600 North Meridian Avenue, Suite 155
Oklahoma City, OK 73116-1411

KIDNEY CONCERNS

SPRING/MAY 2002

ISSUE 40

This Journey Called Life

By: Heather Powell, ESRD Network 13 PAC Member

The sun is shining bright and there is a nice breeze, perfect weather for a motorcycle ride. But this isn't just any motorcycle ride...this is the Motorcycle Ride for Life, a fundraiser for the National Kidney Foundation of Arkansas and, on this Saturday, the 12th of May, 2001, I've been honored with the title of Grand Marshall. As I sit at the front of the pack of over two hundred bikers, engines roaring, I think about the trip ahead and the journey that's brought me here.

When I was 8 years old, my dad won a trip to the Bahamas. When I was 8 years old, I was diagnosed with kidney failure...my parents never made that trip. They had taken me to the pediatrician, because I'd complained about pains in my legs. I was immediately transferred to the hospital for testing...so many tests I can't even remember what they all were. I don't remember being frightened; I didn't understand what was going on. I just remember hating the needles.

I began hemodialysis at Arkansas Children's Hospital. It didn't go well. I was sick every treatment. Though my specific memories of hemodialysis are vague, the friendships I made with the other children there have lasted a lifetime. We went to camp together, played games, shared fears, and encouraged each other. We were our own support group, before there were support groups. The dialysis unit had an Atari for the kids to play and I became an expert on Frogger and Pac-Man, using my feet. I loved school and, though I missed a lot of it, was determined to stay with kids my age; so I always kept up with my studies.

After a year on hemodialysis, I was scheduled to get my mother's kidney. We were in the hospital ready to proceed with the transplant, when the final test showed that, due to all the blood transfusions I had been given, the kidney was no longer a good match. We were all heart broken. I didn't want to continue on hemodialysis and, also, the doctors were afraid I wouldn't last on it. I was failing fast, when we learned about peritoneal dialysis. I switched immediately to PD and my health began turning around.

I was on peritoneal dialysis for four years, when one day the call came; they had a kidney match for me. I received the transplant on May 9, 1987. I can't begin to describe how great I felt. I do not think the words exist for me to explain what a tremendous change occurs with a transplant. I had thought I felt pretty good on PD, but what a difference the transplant made. I did great for the next 2 years.

My senior year in high school I went into chronic rejection. Cyclosporin was then a new drug and they were unsure of the long-term side effects it would have on your body. But when they tried to take me off of it, I had a rejection episode. It was a hard senior year, but I graduated with honors. I went to college on an academic scholarship and studied psychology.

By my second semester, I began to show signs that my kidney was no longer functioning well enough to keep me going. I struggled through for a while, because I did not want to face dialysis again. I dropped out of college twice, due to my poor health. In 1992, after 5 years with a transplant, I went back on PD and back to college, where I graduated in 1997.

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Living with ESRD & Living Well



By: Heather Powell, LCSW , Kidney Patient & ESRD Network 13 PAC Member

I'd like to share with you today some tips that have helped me live with ESRD and do it successfully. Living well with End Stage Renal Disease (ESRD) begins with a choice. Having ESRD is not a choice obviously, but what you do with it is! So, below are 10 tips that I feel have made a definite impact on my quality of life in living with ESRD. A lot of these things are interrelated and build on one another.

1. One of the number one things to have is a **positive attitude**. I have always said that attitude is half the battle in living with ESRD. You can't live as if ESRD is your whole life. It is one part you must learn to live with, but it doesn't have to be who you are or what defines you. You can participate in everyday life like anyone else. Think positive and keep words like can't, quit, and never out of your vocabulary. Do not let a diagnosis of ESRD make you quit or feel as if your life is over.

2. Learn to **laugh** and find the humor in life. It is true that laughter is good medicine, it is even therapeutic. Look for the good in a situation, and be optimistic. There are times to be serious, just not all of the time. Smile - you will find it travels to those around you and makes you feel good. One thing that always makes me smile is my cat. A pet can be a great stress reducer and they are a great example of unconditional love.

3. Have a **support system** in your life. Family, friends, church, anyone you can depend on to encourage you and be there when needed. People who motivate you to do your best and expect it from you. Don't hang around with negative people; they are not a good support and they bring down that positive attitude that you need!

4. Be **determined** in your purpose to live well. ESRD may be a challenge, don't make it an excuse.

5. It is very important to be **educated** about kidney disease, treatment options, and other related issues. When you first learn of your declining kidney function and what is to come, fear is a common feeling. Fear stems from the unknown. The key to fear is knowledge. There are numerous organizations and web sites that provide valuable resources to kidney patients ; utilize the resources available to you. The more you know, the better prepared you feel.

6. **Sharing your experience** will also help to reduce your fear. It helps you to realize you are not alone. You will be surprised at how this simple task will comfort you and give you strength to endure. Sharing with others validates your feelings, gives you a sense of belonging, and gives you a safe place to express yourself to those who really do understand what you are going through.

7. **Be responsible**. While support from loved ones is important, taking an active role in your own health is just as important. You may not always be able to depend on others to make the decision that is right for you. You are ultimately the one responsible for your own well being. Doctors and dialysis staff can tell you what is best for you - it is up to you to do it!

8. **Getting your prescribed treatment** is of utmost importance in order for you to do well, feel good, and live long. Dialysis time, medications, and diet are all significant aspects of your prescription for better outcomes with ESRD.

9. Another essential to living well is **exercise**. This doesn't mean you have to go join a gym. Begin with simple activities that are not too strenuous and build from there. Find an activity you like and do it, as you are more likely to stick with it. The point is to be active. Do not wear yourself out until you are completely exhausted, this sets you up to fail. Instead set realistic goals. You will build up endurance after time, feel energized, and have a sense of satisfaction at your accomplishments.

10. One last thing I find gets your mind off your own problems is to **volunteer and give your time to help others**. There are many places that can use your special talents of experience and compassion. When you give of yourself, you feel good and can see more clearly the blessings in your own life. If you look hard enough, you can find someone who has a greater need than yourself.

I hope these tips encourage and help guide you through your journey with ESRD. ✧

National Kidney Foundation of Oklahoma Presents the 3RD Annual American Indian Kidney Conference

Mark your calendar for July 9,10,11 2002 for the 3rd Annual American Indian Kidney Conference to be held at the Clarion Convention Center in Oklahoma City. The conference will focus on a look at how the Indian Nations battle with diabetes, hypertension and kidney disease and what tomorrow can be for our Indian youth and future generations.

Tuesday July 9, 2002 will focus on the Impact of Kidney Disease in the American Indian Population. Governor Keating and Mayor Humphries will make proclamations for the state and city in a morning ceremony. Representatives from the national office of the National Kidney Foundation, Indian Health Services and the Muscogee (Creek) Nation will present on kidney disease and diabetes.

Wednesday July 10, 2002 will focus on the American Indian Youth Day. This day will focus providing education on kidney disease and steps to prevention to encourage the American Indian youth to take action now to avoid or slow the progression of kidney disease in Indian Nations. The keynote speaker for the morning will be Val Kilmer, a member of the Flathead Tribe. Benjamin Bratt will be a special guest speaker at lunch. A patient panel, "Our Story", will feature current patients who will address issues of diabetes, hypertension, dialysis and transplantation and the impact of kidney disease on their lives and their family's lives. The evening will feature a dinner and awards ceremony to be followed by a Pow-Wow.

Thursday July 11, 2002 is titled Professional Day. This day will focus on educating the health care providers who serve the Indian communities. The topics will look at ways to improve the quality of care and the quality of life for tribal members who battle diabetes, hypertension and kidney disease. The keynote speaker for the morning will be Mitchell Cypress, Chief and Vice-President of the Seminole Tribe of Florida. Continuing Education Credits have been applied for all disciplines.

Representatives from educational and medical/pharmaceutical supply companies will be displaying throughout the conference.

All people are welcome to the conference. If you are interested in attending or want additional information contact Jody Kodaseet, Conference Coordinator, at the National Kidney Foundation of Oklahoma at 405-947-6405 or 1-800-946-6405. We hope to see you there. ✧

Looking For A Few Good Couples

Researchers at Boston College are looking for couples for a new National Institutes of Health funded study called Options on how patients and spouses make decisions about medical care. The researchers are looking for 300 couples to volunteer to join the study. The study involves interviews only. Those who agree to be in the study will participate in confidential interviews four times over a three-year period. To be eligible both partners must agree to participate. The patient must be:

- 55 years or older
- have been on hemodialysis for at least six months
- have been married or partnered for at least five years

Rachel Pruchno, Ph.D., a Boston College research psychologist and Director of the Initiatives on Aging, is the Principle Investigator and Norman G. Levinsky, M.D., a nephrologist at Boston University Medical Center, is the Co-Investigator.

People who have participated in the study have found it to be an enjoyable and thought provoking experience. Information gained from the study is expected to be used to increase understanding of the impact of dialysis on couples and their wishes for the future, and also provide direction for improvements in quality care to both patients and their spouse/partners. To learn more about the study contact Jennifer Rosenbaum toll-free at 1-866-772-3387. ✧

This Journey Called Life (Continued)

The summer before I started graduate school to get my Masters in Social Work, I had a terrible infection and had to go back on hemodialysis. This was a very tough time. I remembered how horrible hemodialysis had been as a child, and dreaded going back on it, but I was left no choice. Thankfully, hemodialysis is better now. I graduated with my masters and learned to do home hemodialysis, so I could work full time. I got a job with the National Kidney Foundation of Arkansas as the Program Director and have now been with them for three years.

This is where my story started. And, as I begin today's motorcycle ride, I realize the journey is not over yet. People ask what has gotten me through these years and how am I so strong? I reply it's not my strength that gets me through, but my Lord and Savior Jesus Christ, my loving and supportive family, sheer determination and a positive attitude. I have a verse that I always go back to when I am feeling down and discouraged. It is Jeremiah 29:11: "For I know the plans I have for you," declares the Lord, "plans to prosper you and not to harm you, plans to give you a future and a hope." I hope I can be an encouragement to other kidney patients out there, because I know it is hard, but I also know you can live a full life! ✧

More Patient Educational Materials Available

FUJISAWA HEALTHCARE INC. has new patient educational material available. The materials include a GIFT OF LIFE: LIVING DONATION video, Find Yourself in Their Experiences patient folder and Transplant Information Kit. Patients can call 1-800-575-6573 to request any of these items. Your facility Social Worker can request quantities of these materials by contacting Lea Mayo Irons at 1-800-695-4321 ext. 3522.

The Full Moon Run: Kidney Klassic 5K was held May 31, 2002 in Tulsa Oklahoma. The run benefitted the American Kidney Fund (AKF) with all proceeds remaining in Oklahoma to assist kidney patients. The race will included a 5K race/walk and 1 mile fun run. Eddie Money performed a free concert after the race. Gates opened at 6PM at 21st and Boulder in Tulsa OK. ✧



Humor Corner



A recent newspaper article suggested that people in the over sixty age group stop eating health food.



After all we need all the preservatives we can get!!!



KIDNEY KONCERNS NEEDS YOU!

Kidney Concerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for Summer/August. 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:

Kidney Concerns
ESRD Network 13
6600 N. Meridian Suite 155
Oklahoma City, OK 73116-1411
1-800-472-8664
www.network13.org

This newsletter is developed while under contract with the Centers for Medicare & Medicaid Services, Baltimore, Maryland. HCFA Contract #500-00-NW13.