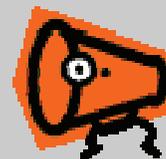


The one Star News etter

A Newsletter for People with Chronic Kidney Diseases and Their Families
The End Stage Renal Disease Network of Texas, Inc. 4040 McEwen, Suite 350 Dallas, Texas
75244 Phone: 877-886-4435 www.esrdnetwork.org

We Have a Voice

By P. Devon Osborne, ESRD patient and member of the Patient Advisory Committee



Special points of interest:

- We Have a Voice
- PAC
- Complaints and Grievances
- Activity
- Dialysis Facility Compare
- Fistula Cartoon
- Super Staff Award
- What a Wonderful World
- NPR
- NxStage Patient Story
- Kidney Contenders
- Recipe
- Yoga for Patients

As you sit in a treatment chair or go through your routines in a dialysis center or at home, it may seem like ESRD and transplant patients do not have much of a voice in the huge medical juggernaut surrounding us. But, there is a voice and that voice was heard very loudly in the halls of Congress last fall. I know because as a dialysis patient, I was one of those voices.

In September 2011, I was privileged to participate in a semi-annual “fly-in” in Washington, D.C hosted by the Dialysis Patient Citizens. There were about twenty patient members from all over the US who assembled on a Tuesday evening and immediately went to work. We were there to talk to our Congress members about two important matters.

First, was House Bill number 2969: “Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011.” Second, was to make sure that ESRD patients would continue to have access to private health insurance in the new Health Insurance Exchanges that are part of the proposed Medicare changes in the Affordable Care Act (ACA).

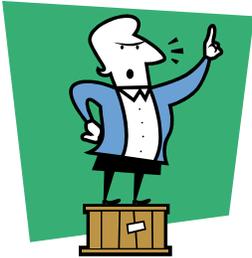
The Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2011 (HB 2969) is, very simply, a bill introduced by Representative Dr. Michael Burgess (R-TX – Fort Worth area) that will extend the Medicare drug benefits to transplant patients so they can continue their Medicare Part D coverage for the life of their transplant.

Continued on page 2 & 3

We Have a Voice continued

Currently, transplant patients lose their drug benefits under Medicare after 36 months following the transplant. The result is that often patients can't bear the burden of the costs of anti-rejection drugs, stop taking them, end up rejecting the kidney and return to dialysis. Our point to the Congress members was that keeping patients on their anti-rejection drugs was far less expensive than returning to dialysis.

Making sure that CKD and ESRD patients have the same access to private insurance, both inside and outside the exchanges created by ACA, was the second issue we were to present. The need to keep in place the Medicare Secondary Payer (MSP) law, which permits ESRD patients to keep their private health insurance coverage for 30 months before Medicare becomes the primary payer benefits everyone involved. Ensuring this protection will mean equal treatment for kidney disease patients and has the potential to save the Medicare program billions over the next ten years. Very early the next morning,



those of us who are in-center dialysis patients, were bused to a local center to get our treatment. The regular first-shift patients and staff graciously came in at 2 a.m. to allow us to use their time slots. After that, we assembled back at the hotel for the first major event of the trip, a conference with Congressional staff members and members of the Congressional Kidney Caucus. A panel of patients spoke of their personal experience with kidney failure and transplants and answered questions from the floor.

That evening we convened for training in the skills we would need for the next day in our meetings with members of Congress or their staff. We were instructed in how to make our points about H.B. 2969 and the Insurance Exchanges. A professional trainer well versed in these matters gave us many pointers and suggestions along with an explanation of how the Senators and Representatives offices operate. By the end of the session, we knew our objectives and were ready to go. We formed groups of two states. In my case, I was paired with DPC members from the state of Oklahoma and fellow residents of Texas. We were given our schedules and told to rest up for the long day ahead.

The next morning, immediately after breakfast, we embarked on our pre-arranged meetings with the Congressional members. In some cases, the Senator or Representative personally met with us and listened attentively. We carefully and quickly made our points as we were instructed. To get even ten minutes in a personal meeting was a special occasion. We were very pleased when Senator Inhofe of Oklahoma spent about twenty minutes with us.

Continued on page 3

We Have a Voice continued

In all we met with the staff of both Senators of Texas and Oklahoma and several of the Representatives from those states. As we were told, in most cases, we met with the Legislative Aide who was responsible for healthcare issues. We were impressed with their knowledge of the specific issues we were there to discuss. Most were pleased to hear what we had to say and were supportive of our needs.

It was an exhausting day for everyone concerned. That evening we convened back at the hotel where I picked up my belongings and made for the airport and returned home. On the trip home I reflected on the fact that I played a small role in advancing the interests of the thirty-six thousand plus dialysis patients in Texas thanks to organizations like Dialysis Patient Citizens. And, now, I'm doing more as a Patient Advisory Committee (PAC) member for the ESRD Network of Texas, Inc. It's a small contribution but it shows that as we sit in our treatment chairs quietly waiting for our life-giving treatments, we have a voice.

For more information on Dialysis Patient Citizens visit:

www.dialysispatients.org



Devon Osborne is a Patient Ambassador for Dialysis Patient Citizens, a member of the ESRD Network of Texas, Inc.'s Patient Advisory Committee and a CDC Infections Control Discussion Panel Member.

Devon can be contacted at devon2002@hotmail.com

Patient Advisory Committee Represents You!

The Patient Advisory Committee (PAC): Your "Voice" at the ESRD Network. To see the complete list of PAC members and the regions they cover, please visit our website at www.esrdnetwork.org and click on **Patients** then click on **Patient Representatives**.

The PAC is a group of patients and care givers from around the state who give feedback to the Network staff and the Medical Review Board about issues that affect the care and quality of lives of patients. We want to have all regions of Texas covered by PAC members. If you are interested in joining this group, please send a letter of interest to the ESRD Network of Texas, Inc., attention: Anna Ramirez or call the Network toll-free at 877-886-4435.

Complaints and Grievances



If I am having a problem with my facility, what can I do?

It is always best to talk to someone at the facility that you trust as a first step. As a patient, you have the right to file a complaint or grievance against your facility. If you feel that you are not being treated fairly or that staff are not doing what they should for patients during treatment time, you may contact the ESRD Network of Texas, Inc. and speak with our Patient Services Department. Our goal is to make sure patients receive the best care possible from their dialysis and transplant facilities.

What happens when I call the Network to file a complaint or grievance?

The Network may decide to investigate the issue or may refer it to the State agency that handles complaints. Unless you give us permission to use your name, your name will not be used during the investigation. In 2011, the Network has received over **500** calls from patients and/or facility staff regarding a wide range of issues. Some of the most common complaints were:

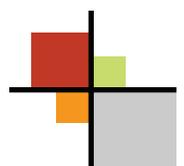
- Staff do not care about patients, do not treat them with respect and speak to them in a rude and negative manner.
- The facility schedules treatment times but does not stick to those times.
- The facility is discharging or 'firing' me without a good reason.
- The staff does not stay in their assigned areas during treatment.
- Alarms go off for a long time before the staff come over to check the machine.
- The facility will not fax patient records.



The Patient Services Department will investigate your complaint and determine what plan of action should be taken for a timely resolution. The Patient Services Coordinator may make a visit to the facility, recommend additional staff training or do a patient survey to see if other patients are experiencing the same things that you are. Sometimes immediate action needs to be taken. In those situations, the Network will send the complaint to the Department of State Health Services to investigate. The State may survey the facility and/or interview staff and patients.

What does the Network do with this information?

Every 3 months the Network reviews all the complaints and grievances that have been filed. If a facility has 3 or more complaints during a 3-month period or 4 or more in 6 months, the Patient Services Coordinator will contact the facility and make recommendations on how the facility can reduce complaints. Sometimes the Network will require the facility to develop an improvement plan that the Network will monitor for a period of time. The Network makes every effort to resolve complaints in a timely manner. If you, as a patient, ever feel that you are not receiving the best experience of care, please speak with your facility administrator or call our Patient Services Department for assistance toll free at 1-877-886-4435.



??? What to do if you have a complaint ???

If you are unhappy with the care or treatment you receive at your dialysis clinic or transplant center, or if you have a complaint about your care, you have the right to file a complaint.

Here is how to file your complaint:

- ⇒ First, try to talk to your nurse, doctor, or social worker about the problem. It is possible there is a simple explanation. Even if there is not a simple explanation, it may be possible for you and the clinic to work out a solution to the problem that could result in better care for you and other patients.
- ⇒ Next, if talking does not resolve the problem, or if you feel you cannot discuss your problem with the staff at your clinic, you can go directly to the regional administrator or even the corporate office of your dialysis company or transplant unit. The names and phone numbers of these people should be posted in the waiting room of your clinic.

Finally, if none of the above actions work or if you feel your clinic or corporation cannot help you, call one of the toll free numbers below for help.

Texas Department of State Health Services	or	The ESRD Network of Texas, Inc.
(888)-973-0022		(877)-886-4435

If you contact the Network for help, WE CAN:

- ⇒ Give you names and phone numbers of people you can speak to at your clinic's corporate offices.
- ⇒ Give you information about Medicare regulations and your rights under Medicare.
- ⇒ Contact the clinic and conduct a **confidential** investigation into your complaint, which may include one or more of the following actions:
 - Request medical records
 - Interview staff members or patients and asking for details about a complaint
 - If necessary visit a clinic in person

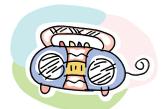
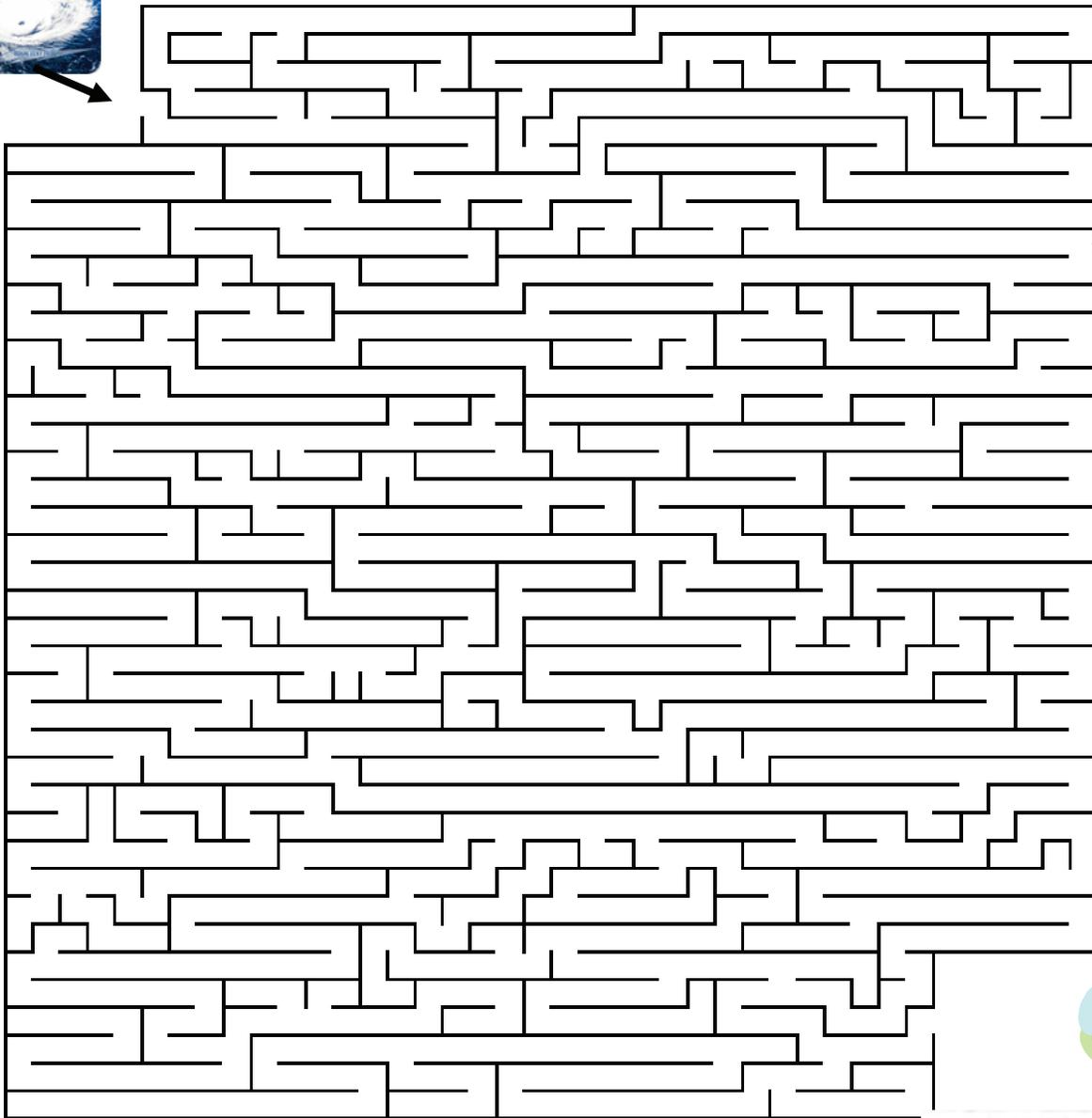
Remember: Confidential means we will not tell anyone at the facility or clinic your name, unless you give us permission to do so.

If you contact the Network for help, WE CANNOT:

- Force a clinic or doctor to accept a patient.
- Guarantee you can choose which staff members put your needles in.
- Change or get involved in anything that has to do with personnel policies and procedures.
- Get a doctor, nurse or patient care technician "fired" or transferred.



Make your way through the maze to reach the items you need on the right side of the page to prepare for this hurricane season.

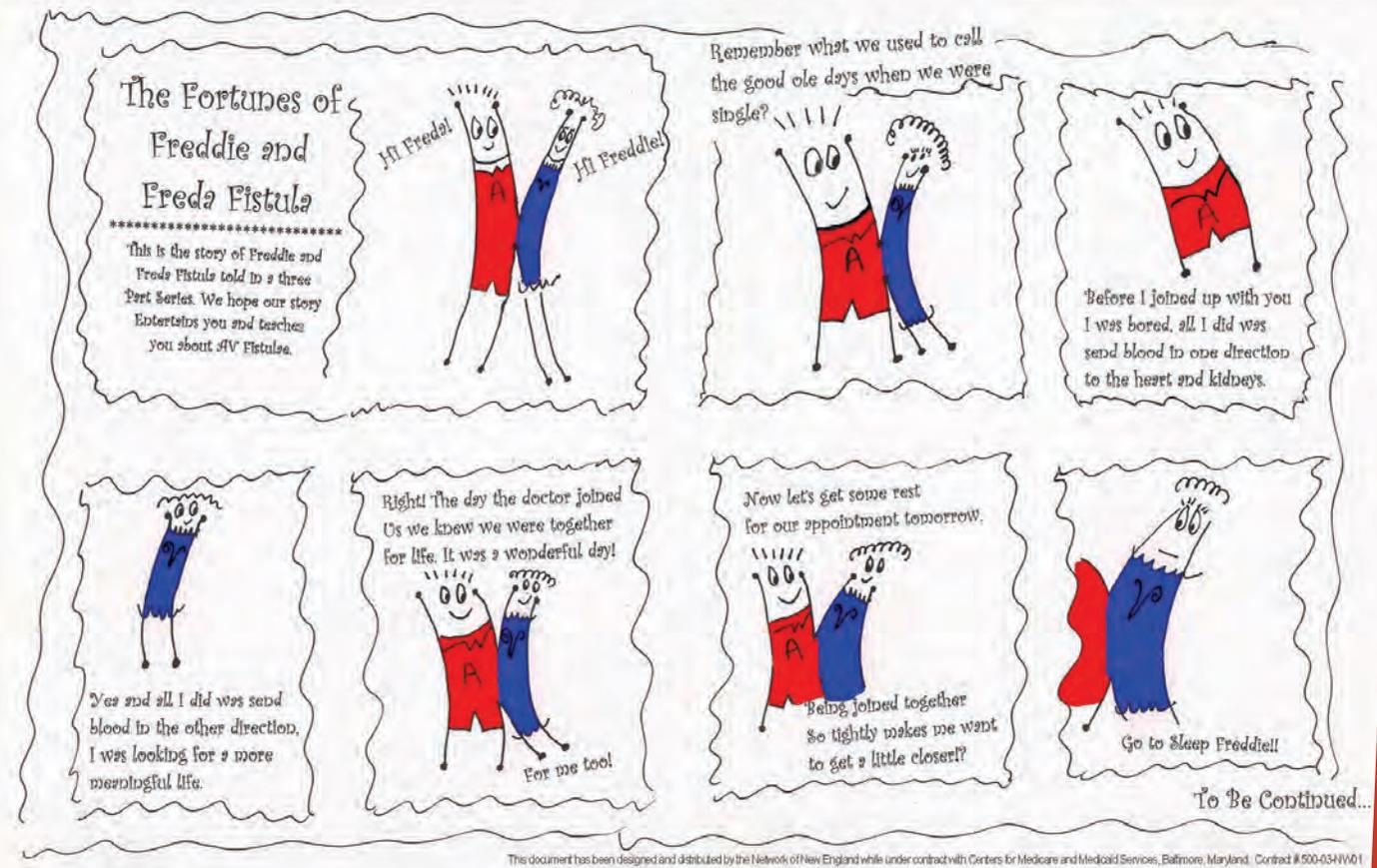


For more information on disaster preparedness go to page 18 or visit the Texas ESRD Emergency Coalition website at www.texastec.org



Compare Dialysis Facilities in Your Area!

The **Dialysis Facility Compare** tool, located at www.medicare.gov/dialysis, is a tool to help you find dialysis facilities in your area. It has detailed information about Medicare-certified dialysis facilities and other resources for people with kidney disease. You can use this information to compare the services available and the quality of care provided by facilities in your area and around the country. Contact the Network for a flyer about how to use this valuable tool. **Network: 1.877.886.4435**
 Dialysis Facility Compare Website: www.medicare.gov/dialysis



Share Your Story!

The Network is always looking for patient stories for The Lone Star Newsletter. We need your stories in order to make a successful newsletter, pictures are always welcome as well.

If you would like to submit a story or make a suggestion for the Newsletter please contact Anna Ramirez at aramirez@nw14.esrd.net or call 1-877-886-4435.



Super Staff Award

The Network wishes to congratulate the following exceptional staff for their excellence in patient care:

Hahn Truong and Hai Nguyen from Sohum East Houston Dialysis Center (both pictured) nominated by Michael Johnson.



Claudia Liara, CCHT and Judy Mueller, RN from FMC Cleburne Dialysis nominated by Bob Collins.



If you have a staff member that went above and beyond, or always provides excellent care to you or others, please nominate him or her for a super staff award so his or her hard work can be recognized. You can nominate him or her by contacting Anna Ramirez at aramirez@nw14.esrd.net or 1-877-886-4435, or by sending the following information to the Network either by fax or mail.

Your name

Super staff's name and his or her position

Facility name and address

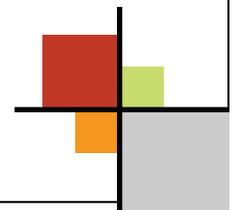
Brief description of why you want to nominate them



Network fax #: 972-503-3219

Network address: 4040 McEwen Rd Suite 350, Dallas, TX 75244

We will include pictures of staff with their awards and who nominated them if you will send copies to the Network.



Coping with Chronic Kidney Failure

Denise Eilers, RN, BSN

*What
a
Wonderful
World*

On a balmy night in April, 2007, my son Marty married an amazing and beautiful young woman. At the reception, although I was surrounded by my family and friends, I nonetheless felt myself sinking into self-pity. What a bittersweet event! While I was ecstatic about the wedding, I was infinitely sad because Jerry, Marty's Dad and my husband of 35 years, was not there to share the magical moments. After dinner, the bride and groom took to the dance floor and the Louis Armstrong rendition of "What a Wonderful World" began to play. As if on cue, the accumulated memories from my own marriage came flooding back, and I began to smile as I thought of all the wonderful moments that had brought me to this time and place.

Anyone who did not know my husband and I well would have been terribly confused by my attitude. After all, my late husband was on home hemodialysis for just shy of twenty five years, from 1980 until his untimely death in 2004. Largely because of misinformation and media portrayals, dialysis is often seen as "a fate worse than death." For us, nothing could have been further from the truth. My husband worked full time as a CPA, played golf several times a week and volunteered in our community. Together, we renovated an old home, traveled, socialized, raised our son—and had loads of fun along the way.

Was life always easy? Of course not! Were there glitches along the way? Absolutely! But then, life in general is not always a smooth road. If there was any secret to our success it was that we functioned as a team—both in our marriage and throughout our dialysis experience. We gradually gained valuable insight and coping skills.

Learn

When my husband began home dialysis training, he self-assuredly told our training nurse: "I intend to get this done faster than anyone else." He made good on that statement, focusing on gaining the knowledge he needed to "go home." Most of our friends assumed it was rather easy for us, since I am a nurse. However, I quickly realized that partnering with a loved one is vastly different than caring for one of my patients.

- * Stay informed and updated on kidney issues. Knowledge is power and builds confidence.
- * Learn about all chronic kidney failure treatment modalities and YOU choose the one that best fits YOUR lifestyle.
- * Learn about and practice healthy lifestyle habits just like anyone else—diet, exercise, sleep and relaxation.

Continued on pages 10-14





- * Analyze and talk about both good and bad experiences, learn from them, and make needed changes.
- * Break learning down into small, manageable parts.

*What
a
Wonderful
World*

As one nephrologist says, “If you can drive a car, you can learn to operate a dialysis machine safely.”

- * Go with your loved one/partner to appointments—take notes, ask questions, get clarification and be supportive.

Live

Our son never knew anything other than “Dad on dialysis.” He and his friends never considered the process weird or scary. It was simply a part of our family life. Jerry was fond of one line catch phrases, one of his favorites being “gotta eat, gotta sleep, gotta work, gotta dialyze. No big deal. Besides, I can watch the Packers, the Braves or the Iowa Hawkeyes without Denise giving me a household gotta do list.”

- * Dialyze to live, rather than live to dialyze.
- * Keep working if at all possible. Not only is it self satisfying but it makes good economic sense. Life doesn’t need to stop because of kidney disease.
- * Take control and don’t let dialysis rule your life. Fit it into your schedule.
- * Channel any anger into positive action & talk about the feeling in a calm way.
- * Find meaning and purpose in life. Volunteer, mentor others or educate the public. Even simple things like offering to make phone calls for a non profit organization gives a ego boost. Volunteer to talk with and support newly diagnosed dialysis patients.

Laugh



Nothing funny about dialysis? Oh, really? I have a catalog of funny stories. One of my favorites involves Jerry's wacky sense of humor. (Spoiler alert: Please remember that I am a nurse by profession.) Shortly after starting home dialysis, my husband came home from work one day and asked if it was okay to invite a new coworker and his wife to dinner, a couple who had not yet met me. When the evening arrived, the pair seemed a bit uncomfortable as Jerry began explaining dialysis and his treatments. When I chimed in that I was Jerry's care partner and in-house nurse for home dialysis, the man visibly relaxed, then said: “What a relief! I am sorry if I was acting strangely, but your husband told me he was sleeping with his dialysis nurse. I thought he was having an affair.” All four of us laughed until we were nearly breathless.

- * Find humor in dialysis/CKD. It is better to laugh than to cry.

Continued on page 11

What a Wonderful World

- * Find the “funny” in ordinary situations.
- * Laugh every day whether it's while watching a sitcom, perusing the comics or telling a joke. Laughter really is the best medicine.
- * Act silly once in a while. Be a kid occasionally. Snow angels and pillow fights work.
- * Take your health seriously, but don't take yourself too seriously.
- * If all else fails, “soitenly” watch the 3 Stooges...n'yuk, n'yuk, n'yuk! We did.

Love

I will never forget one special wedding anniversary. After work, Jerry trudged in the house and then apologetically said, “Honey, I left my wallet in the glove compartment.” Since he acted as if he didn't feel well, I volunteered to go out and retrieve it. As Jerry watched from the kitchen window, I slid in the car, opened the glove box and found it empty except for a single small, elegantly wrapped box. Underneath was a note that said, “Gotcha! Happy Anniversary, love.” The pearl bracelet was lovely, but the idea was priceless.



- * Be a spouse. CKD/dialysis doesn't absolve us from that role of spouse—or mother, or brother....
- * Date your spouse and keep the romance alive.
- * Be affectionate—hold hands, cuddle up or whatever.
- * Cry together, if need be. Tears are not a sign of weakness, but can be cleansing and healing.
- * Discuss fears openly—nothing is too trivial if it is of concern.
- * Don't lose track of what attracted you to each other. If necessary, make a written list.
- * Remember that physical limitations are just physical.
- * Listen to each other's viewpoint without judging.
- * Find a private place that is soul-refreshing. It can be somewhere as simple as a favorite garden spot, a quiet corner of the house or a friend's brick patio.
- * Take a break from children.
- * Remember that it's okay to resent the condition. Don't resent your partner.

Simplify

It was Christmas 1998, and, according to our long standing tradition, I was set to host my husband's family for an elaborate “Saturday before the big day” dinner. Being something of a Martha Stewart, I usually looked forward to planning every single detail.

Continued on page 12

This year, however, Jerry had just been discharged from the hospital, his first such stay in nearly 20 years. We were both exhausted. On a whim, I decided to serve a simple chili bar with all the toppings—cheese, taco chips, sour cream and more. At the last minute, since there were children coming, I added a bowl of colorful Christmas sprinkles to the buffet. That simple humorous touch was the hit of the evening.

- * Don't drop out of activities. Rather scale back, if needed.
- * Find time for day jaunts. Every vacation doesn't need to involve airplanes, long distances and high cost. Even a road trip within an hour or two drive can be a much needed break. If you don't feel like driving, ask friends to come along.
- * Realize that you don't have to be a Rachael Ray or Bob Villa.
- * List what simply must be done and don't worry about the rest.
- * Enlist the help of family and friends. Most of the time, they are just waiting to be asked.
- * Shortcut cooking and cleaning. Ladies, it's okay—really, it is!
- * Entertain more simply. Note: See above story!

Connect



My ladies coffee group has been a tradition for nearly 25 years. Composed of about a dozen women of disparate ages, marital status and politics, the group meets every day but Sunday at a local coffee shop. Anyone who is free drops in. Despite our differences, we have been through births, marriages, graduations, divorces, deaths and every other conceivable joy and sorrow in life. Without those women and their support, I wouldn't have been able to cope as well. Ditto that for Jerry and his golf buddies!

- * Stay in the loop with family and friends. If you can't get together, keep in touch by snail mail, email or phone calls.
- * Stay involved with clubs and church.
- * Reach out to friends—they may hesitate to call or may not know what to say.
- * Give people as much information as they want, but don't dwell on your condition.
- * Keep in touch with the outside world. Read the local newspaper or watch the local news.
- * Seek out others in the same situation for support. Computers have made this easy. However, make sure you seek out legitimate sites with quality information.
- * Connect with your health providers. Keep a list of questions for each visit and don't hesitate to ask them.

Continued on page 13



Chill

*What
a
Wonderful
World*

Everyone has their own ways to relax and reduce stress. Jerry loved to stand on our front porch to watch the first snowfall of the year. One especially bad winter, the first snow was a 6 inch blizzard. As I stepped outside to join him, a snowball whizzed by my head. What followed was an unplanned no-holds-barred snowball fight, which expanded to include several of our neighbors. We were literally chilled, but oh so relaxed.

- * Develop a hobby that you love. Jerry was a golf addict, I loved cooking and antiquing.
- * Learn to “go with the flow.” In the overall scheme of life, most things are trivial and not worth upset and worry.
- * Smile—it works.
- * Learn to recognize burnout—symptoms may be fatigue, grouchiness, and depression—and take a break.
- * Relieve stress in a positive manner—walks, sports, movies, music, shopping, or books.
- * Take a “virtual” holiday complete with food, music and travelogue movie.
- * Pamper yourself. For women, a mani-pedi, massage or make up makeover is relaxing. Many large department stores offer free “spa” days in the cosmetics and fragrances department with no obligation to buy.
- * Acknowledge that negative feelings are acceptable. It’s how we deal with them that counts.

Dream

Our dream come true arrived on January 13, 1982, in the form of a 9 lb baby boy we named Marty. After a few sleep interrupted and nervous nights, Jerry yawned and quipped, “Wow, this parenting thing is going to be so amazing but difficult. Dialysis is a breeze by comparison.”

- * Make plans for tomorrow, next week, next month and even next year.
- * Looking toward the future solidifies the idea that there will be a future—a good one.
- * Set realistic goals. Make them attainable.
- * Reminisce.
- * Work at creating happiness—it doesn’t just happen.
- * Appreciate what you have. When we visited the University of Iowa for clinic appointments, Jerry would look around and realize that so many people had worse problems than he.

Continued on page 14

Dream

- * Focus on finding joy in simple things—a quiet walk, a good book or movie, or an ice cream cone on the first warm day.
- * Reassess what is important in your life.
- * Think about something wonderful in your life each day. The power of positive thinking can't be overstated. The corollary, though, is not to feel bad for having “down” days. Everyone does.

Above all, we learned one basic truth: Don't be hard on yourself or go on a guilt trip. Being on dialysis or being a care partner doesn't automatically make a person perfect. You carry your former self into this new chapter in life. You are the same person as before with the same hopes, dreams, fears and goals. Being able to pursue those goals—and achieve them—is as important now as before, possibly even more so.

While all these coping skills are vital for anyone and not just dialysis patients and their care partners, perhaps the ultimate secret to success is this: To make an honest attempt to appreciate what is in the other person's mind, to listen with our hearts to the unspoken words, and to let our souls connect.

**“I see trees of green...red roses too
I see 'em in bloom...for me and for you
And I think to myself...what a wonderful world”**

*Contact Information: Denise Eilers, BSN, RN
14 Kenwood Avenue Davenport, IA 52803
563-322-3659 Home
563-508-4883 Cell*



We Need NPRs

What is a Network Patient Representative (NPR)?

Each clinic is asked by the Network to appoint at least one **Network Patient Representative (NPR)** to be a contact person between the clinic patients and the Network. Some clinics have a Representative for each shift or each dialysis day. **We need more NPRs !** If you would like to be considered for the NPR position at your facility, speak with your social worker about the job.

Word Search

E B U V V A C A T I O N E
 S P A H Y D A Z C F Q I E
 U I I P O R Z X H A D L S
 M Y V P G R E H E M Q I Q
 M D E Z A E R A E I I P E
 E W I C W O R L D L G P L
 R K A C I S T B C Y I R W
 C W E N L A E V O I C E B
 Y Y M T E S I E L L N P T
 P E M O O M D Y L D J A A
 M L X T R A I L M I X R L
 B R E A T H E A E D C E H

Word Find

Voice
 Anemia
 Summer
 Prepare
 Yoga
 Ready

World
 Family
 Vacation
 Trail Mix
 Breathe



KIDNEY CONTENDERS

Featured in this picture is team Kidney Contenders. Most of the participants were from Acme Brick in Elgin, TX



They turned out to support Jeff Reat. He is a driver for Acme and also a kidney cancer survivor. Thanks to everyone for their participation.

The 2nd annual Austin Kidney Walk was held on Saturday, May 11, at Lake Pflugerville. The Walk was sponsored by the National Kidney Foundation and all proceeds went to NKF. On Friday night, May 10, Kidney Contenders, a local group, held a Pre-event kickoff at the Tap Room in downtown Austin. There the “Music meets Cause” event featured several local bands along with a silent auction. Many patients and their families donated hand crafted art pieces for the auction. The auction was held over until Saturday. Both events had a good turnout, everyone had a great time, and money was raised for a great cause.

A NxStage Patient's Story



My name is Kevin Richard, and I am a 28-year-old African-American dialysis patient. At 18, I was diagnosed with a rare kidney disease that primarily affects African-Americans. Swollen legs and protein in my urine were the first signs of a kidney problem, but the kidney biopsy revealed that I had FSGS. At 19, I felt alone, ashamed and scared. I did know what dialysis was. I had heard the word, but I never thought it would happen to me.

At 19, I felt invincible. I had a bright future and dialysis did not fit into that future. However, as I lay in the hospital bed, my entire existence had changed. A new chapter had opened in my life and I was not prepared for this rollercoaster called dialysis. I spent five years on dialysis while attending the University of Houston majoring in English. Although I was on dialysis, I was determined to finish school because I had had aspirations to help others. In college, I interned for Writers in the School with Texas Children's Hospital in the renal department teaching Creative Writing to children on dialysis. The University of Houston awarded me for my efforts with the Crane Award, but the true reward came from giving others hope. I never let my circumstances prevent me from achieving my goals. I wanted to be an inspiration to all those children on dialysis.

Continued on page 17

During those five years, I experienced most of the side effects that accompany dialysis. The weakness, severe muscle cramps, blood pressure drops, darkening of my skin complexion and deep depression. I was angry and withdrew from friends and family. I was upset because I lacked a support system of other dialysis patients. I was not fully educated on dialysis and its affects. I learned from my experience. I wanted a community I could reach out to. In 2007, I discovered the nocturnal dialysis at DaVita and the buttonhole technique.

Nocturnal dialysis was an improvement from the traditional in-center because it was a slower continuous pull for eight hours. However, it was difficult to maintain a healthy sleep pattern with school, work, and my internship. I was also introduced to the buttonhole, which was a wonderful way to preserve a fistula and minimize scar tissue and aneurysms. It also preserves the life of the fistula by cannulating the fistula with a blunt needle rather than a sharp one in the same spot. That same year I received a transplant.

In 2009, my transplant failed, and I was back on dialysis. My life had changed. I was now teaching Kindergarten and my school had long hours. My endurance was greatly impacted by the dialysis “wash-out” most patients experience. In-center dialysis interfered with my work schedule and ability to travel. I felt trapped and hopeless.

Then, I discovered the NxStage program through U.S. Renal. My nurse Tara Kennedy made the transition very easy. She was willing to go above and beyond to assist me with the transition. I was shocked at how hard she worked and her patience. She has become a part of our family. NxStage changed my life because I regained my independence. I no longer suffered the ill effects of in-center “wash-out.”

After each treatment I felt strong and energized. I never thought it would be possible to be strong after dialysis! The NxStage machine is small, easy to setup, clean and transportable. I went from taking four blood pressure medicines to one! I felt in control of my life again. At first, I was intimidated by the thought of treating at home. However, it was easy to learn and now I treat on my own schedule. I recommend NxStage for anyone on dialysis. Please research the program and contact your doctor or social worker and ask.



It could change your life! It changed mine.

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Curriculum and Instruction with a concentration in Reading from Concordia University. He also created his own blog called www.connectingthadotz.com

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SAVE A LIFE

WHAT DIALYSIS PATIENTS NEED TO KNOW ABOUT EMERGENCY PREPAREDNESS....



Being without dialysis as few as three or four days could result in illness or even death for individuals with kidney failure. Each dialysis facility must have a facility-specific disaster/emergency plan. In an emergency, do you know:

WHERE TO GO? WHAT TO DO? WHO TO CONTACT?

Plan ahead and Be Prepared! Follow the TIPS provided below:

- Make an emergency supply kit*
- Keep an updated medicine/allergies list*
- Create a personal evacuation plan*
- Talk to the healthcare team about the facility emergency plan*
- Keep a record of your important personal information, facility's name, physician and emergency contact information*
- Give your healthcare team out-of-state contact numbers*
- Get a copy of the emergency diet and keep emergency supplies on-hand*
- Plan for back-up transportation to dialysis*
- Get a list of dialysis facilities in the area*
- Follow the same frequency for dialysis services when possible*
- Put documents in your clear disaster bag*
- Review your **READY** Packet with a member of your healthcare team*
- Visit the **Texas ESRD Emergency Coalition (TEEC)** website at www.texasteec.org**
- Watch the **TEEC Disaster Preparedness** video with your fellow patients (coming to your clinic soon)*
- Fill out your lavender vital information card from the **KCER** website at <http://www.kcercoalition.com/lavender.htm>**

*If you do not have access to the internet, ask your social worker to print off materials for you.

For additional information about disaster planning please visit
www.texasteec.org or <http://kcercoalition.com/>

On the go this summer? Try this Honey Maple Trail Mix!

Recipe from Davita, Inc.

Portions: 24 Serving size: 1 cup



Ingredients

- 3 cups Golden Grahams® cereal
- 5 cups Rice Chex® cereal
- one 10-ounce box Cinnamon Teddy Grahams® snack cookies
- one 6-ounce bag Pretzel Crisps® or one 10-ounce bag mini pretzel twists
- 1/2 cup unsalted butter or tub margarine
- 1/3 cup dark brown sugar
- 1/4 cup honey
- 1/4 cup maple syrup
- one 5-ounce bag dried cranberries or Craisens®
- two 3-ounce bags Crispy Granny Smith Apple Chips®

Preparation

1. Combine Golden Grahams, Rice Chex, Teddy Grahams and pretzels in a large bowl.
2. Melt butter in a small saucepan; add brown sugar, honey and maple syrup. Cook over low heat until sugar is melted.
3. Pour over cereal mixture and mix well until all pieces are coated.
4. Preheat oven to 325° F.
5. Prepare 3 jelly roll pans by lining with aluminum foil and spraying the foil with cooking spray. (Can be done in 3 batches). Spread cereal mixture evenly over pans. Bake at 325° F for 20 minutes; stirring once halfway through.
6. Mix cranberries and Apple Chips; divide evenly among pans and stir.
7. Bake 5 more minutes; cool completely and store in an airtight container.

Nutrients per serving

- Calories: 262
- Protein: 3 g
- Carbohydrates: 47 g
- Fat: 9 g
- Cholesterol: 11 mg
- Sodium: 178 mg
- Potassium: 84 mg
- Phosphorus: 66 mg
- Calcium: 63 mg
- Fiber: 1.8 g

Helpful hints

- If you have diabetes, reduce portion size to 1/2 cup for a lower carbohydrate snack.
- Look in the produce section for apple chips if you do not find it in the snack section.
- Share extra servings with family and friends or cut recipe in half to make less.

Yoga is Therapy

Benefits of yoga for Patients with a Chronic Illness

By: Corinne Clynes, RN, BSN, RYT 200

Yoga is therapy. For a patient with a chronic illness yoga can be used as an essential part of therapy. Chronic illness disturbs the body's natural state of equilibrium. We can look at the body as a dynamic state of mind, body and spirit. Chronic illness creates a disturbance in all three of these aspects of our body. Yoga when implemented on a consistent basis allows the body to tap into its own natural healing ability and allows the body to heal at a more optimal level.

Yoga means to "yoke" or to unite mind, body and spirit. The history of yoga dates back to 3,000 B.C. the great yogis of those days would implement different poses as a means to heal the body. Each posture in a yoga sequence is used to heat the body, increase flexibility and detoxify the body. Each yoga posture aids in realigning the skeletal structure of the body and ridding the body of unwanted waste.

For example, Surya Namaskara A, also know as sun salutations help to stretch and realign the spine as do other yoga postures. One example of assisting the body in getting rid of unwanted toxins is through the use of twisting postures. In yoga, the twisting of internal organs helps to ring out the internal organs, ridding them of unwanted toxins. B.K.S. Iyengar, one of the world's most respected teachers of Yoga, describes twists as a "squeeze-and-soak" action: the organs are compressed during a twist, pushing out blood filled with metabolic by-products and toxins. When we release the twist, fresh blood flows in, carrying oxygen and the building blocks for tissue healing. Side twists, forward bends and back bends are all poses that would benefit the internal cleansing of the kidneys. To see examples of these postures visit the following website: http://www.yogajournal.com/poses/finder/browse_categories. Forward folds are good for compressing the kidneys to help aid in detoxifying the kidneys.

Yoga can be practiced anywhere! For those of you that can tolerate some heat, an early morning outside practice at the park is great, it helps to clear the mind. Take a friend with you! Practice at home if the heat is too much, find a quiet area free of distraction. Practice in front of a window that has nice scenery or in a comfortable room, light a candle and play soft music; this helps to create a feeling of calmness and peace. It is the summer and the weather is getting warmer, so always remember to hydrate before a yoga practice and eat a small meal an hour before practice. It is advised to take small sips, not gulps, of water during practice so you don't upset your stomach.

Continued on pages 21-22



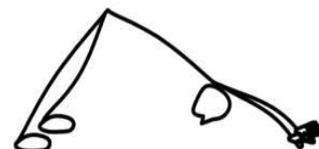
YOGA



Chronic illness breaks down the body's own natural defense system, decreasing immunity and energy. That is why it is important to take care of your body as a whole, even if faced with a chronic illness. Yoga is designed to help realign the body so we can increase our own body's natural healing abilities. Through a combination of yoga postures (asana), breath control (pranayama) and calming of the mind (dhyana or meditation) the body can prepare itself for a better state of being, and optimal healing can occur. The benefits of yoga are many: decrease fatigue, depression and anxiety and an increase in energy, flexibility and healing. Also, for those of you with insomnia, there are poses that can help further relax the mind and body and prepare you for rest. For example, lying on the left side of the body in a fetal position or legs up the wall and focusing on your breath. Yoga takes patience and dedication. Start slow and learn to listen to your body. Find a practice you enjoy. Kundalini and Restorative yoga are great forms for anyone, especially when energy levels are low and we need to move slowly due to a chronic illness. Start with a beginning Vinyasa flow (which is described as a flowing class linking the breath with movement) or Hatha yoga (a more dynamic form of yoga combining strength and movement). Both classes are great for those that feel they are able and ready to move. Classes are specifically designed to assist in healing different ailments of the body.



Downward Facing Dog →
 ← **or Down Dog**



A Basic Yoga Sequence for Beginners:

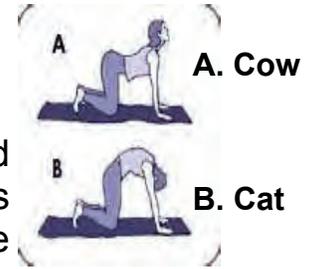
- 1) Start by finding a comfortable space free from distraction. Maybe light a candle, dim the lights and play soft music. Sit in a comfortable cross-legged position (Sukhasana) or one that is comfortable for you, close your eyes and focus on the breath. In yoga, we use the Ujjayi breathing technique. Both the inhale and the exhale should be steady and even, the length of the inhale should be the same as the length as the exhale. Start with a count of five for each inhalation and exhalation. With each inhale feel the belly rise (as if there is a balloon inside the belly inflating), and then use the breath to feel the lower, middle, and upper rib cage expand, and then feel the upper chest expand (or lift). With each exhalation focus on exhaling first from the chest, then the rib cage and exhaling all the air out by encouraging navel towards spine (deflating the imaginary balloon). Do this five to eight times. *Always listen to your body, do less or stop if feeling dizzy or short of breath.

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YOGA



2) Next, staying seated, start with light movement such as head rolls or cat-cow stretch (which begins on the hands and knees with the spine long and head neutral, then on the inhale arching the back and on exhale rounding the spine, tucking the chin towards chest and drawing navel towards spine) x 3-5 sets then, slowly moving yourself into a downward dog position (which can be described as an upside down triangle, pressing your hips and tailbone towards the sky, the spine is long the neck is relaxed and our gaze is toward our belly button or knee caps, feet are hip distance apart and hands are shoulder width apart, pressing down activating the hands, fingers and feet). Then coming back onto your hands and knees for another cat-cow stretch. Ending in child's pose (knees bent, buttocks resting on heels, forehead to floor arms straight out or along side of the body). Repeat this sequence three times, focusing on your breathing. To see examples of these postures, visit: the following website: http://www.yogajournal.com/poses/finder/browse_categories.

- * In yoga we use an inhalation to move into postures that expand, lift or lengthen the body. We use an exhalation to move into postures that fold forward, twist or round the spine. In a flowing class, we connect each inhalation/exhalation with a movement and each asana/posture that we hold use at least three to five breaths using the breathing technique explained.



Savasana

3) Always end your practice in Savasana or corpse pose, which can be described as lying on your back palms facing up, arms away from your body and gently allowing the legs to relax with a couple inches in-between them. Resting here with your eyes closed for 5 to 10 minutes, then slowly wiggle your fingers and toes to bring awareness back to your body, returning to your day feeling more peaceful! Feel the difference in your inner self after your practice. Hopefully you feel more centered, balanced and relaxed! *Namaste'*

- * As with all exercise, consult your doctor before beginning a yoga program. This article and the information it contains is not intended to cure any illness or disease.
- * There are many forms of yoga and many different postures in yoga, find a practice that suits your needs. Each pose in yoga can also be modified to meet the needs of a beginning yoga practice.
- * Be kind to yourself and always listen to your body. Yoga is not a competition, so do not compare yourself to others. Over time you will be surprised to see how much the body can open and move with consistent yoga practice.

Network 14

Who We Are?

The End Stage Renal Disease Network of Texas, Inc. (ESRD Network) is one of 18 agencies that work under contract with the Centers for Medicare & Medicaid Services (CMS), the federal agency that runs Medicare. Your ESRD Network, which provides support to the Texas dialysis and transplant community, is located in Dallas, Texas. The other 17 Networks are located regionally across the country. The Networks perform many important jobs for the dialysis and transplant community, including:

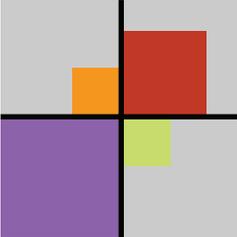
- Collecting and analyzing data about dialysis and transplant patients and their treatments
- Evaluating the quality of care and services provided to dialysis and transplant patients
- Supplying professionals with clinical information and data they can use to evaluate and (if needed) improve their services
- Maintaining a grievance procedure to investigate patient complaints about the quality of care provided by dialysis or transplant units

The Network is made up of several volunteer committees-the Executive Committee, Medical Review Board, and Patient Advisory Committee. Each committee is made up of patients and professionals. The committees provide guidance and support to help the Network meet its mission and goals.

Our Goals

To improve the quality of care for persons with ESRD and to make sure that this care is medically necessary, efficient, high quality and consistent with professional knowledge.

To provide CMS, the Texas Department of State Health Services, and the dialysis and transplant community with information and data related to the Medicare ESRD program and the ESRD population.



**Check out the Who We Are Webinar
located on our website at
www.esrdnetwork.org, under the social
worker tools and resources tab!**

Resources and Important Numbers and Websites

Kidney School

www.kidneyschool.org

One of the BEST **resources** available for almost everything you need to know about kidney failure, dialysis and transplant. This site is organized into interactive, self-paced chapters.

Texas Department of State Health Services (TDSHS)

1-888-973-0022

www.dshs.state.tx.us

Medicare

Customer Service Line

1-800-813-8868

www.medicare.gov

Medicare Part D

Updates and Information

www.medicare.gov

American Association of Kidney Patients (AAKP)

800-749- AAKP

www.aakp.org

Renal Diet Information

www.mrstdash.com

www.andrew.cmu.edu/user/sorensen/

Bureau of Kidney Health

1-800-222-3986

www.dshs.state.tx.us/kidney

United Network of Organ Sharing (UNOS)

1-800-292-9547

www.transplantliving.org

American Kidney Fund

1-800-638-8299

www.akfinc.org

The Renal Support Network (RSN)

1-818-543-0896

www.renalnetwork.org

Modality/Treatment Options

www.homedialysis.org

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The End Stage
Renal Disease
Network Of Texas