DPC EDUCATION CENTER

THE KIDNEY CITIZEN

A publication of Dialysis Patient Citizens (DPC) Education Center

President's Message

On behalf of the Dialysis Patient Citizens (DPC) Education Center Board of Directors, staff and volunteers, I want to thank you and all of our donors for your continued involvement and support. This past year was a busy year at the DPC Education Center. We improved access to patient-driven education materials, provided additional resources and trainings for patients to become more active in their care, and collaborated with multiple partners to bring the best ideas to the table to advance patient care.

Our work is far from over. As a kidney failure patient, I understand the challenges that kidney patients continue to face in caring for their health and having access to accurate and empowering educational information. In 2017, we plan to: create new opportunities for patients to support one another in their care, add new interactive resources to our website, produce more educational resources in Spanish, and work even harder to reach renal patients in support of their efforts to delay and potentially prevent kidney failure.

Our organization cannot continue its mission and serve kidney disease patients like you without the strong support of the kidney community. We need your continued assistance to carry out and fulfill our mission. One way you can help is to mail in a contribution in the enclosed envelope. Your donation will go directly towards helping us increase public awareness to prevent and delay the progression of kidney disease. We greatly appreciate each contribution no matter how small to help us achieve our goal.

I hope I can count on your support as we work together to improve the quality of life for all kidney disease patie

Sincerely

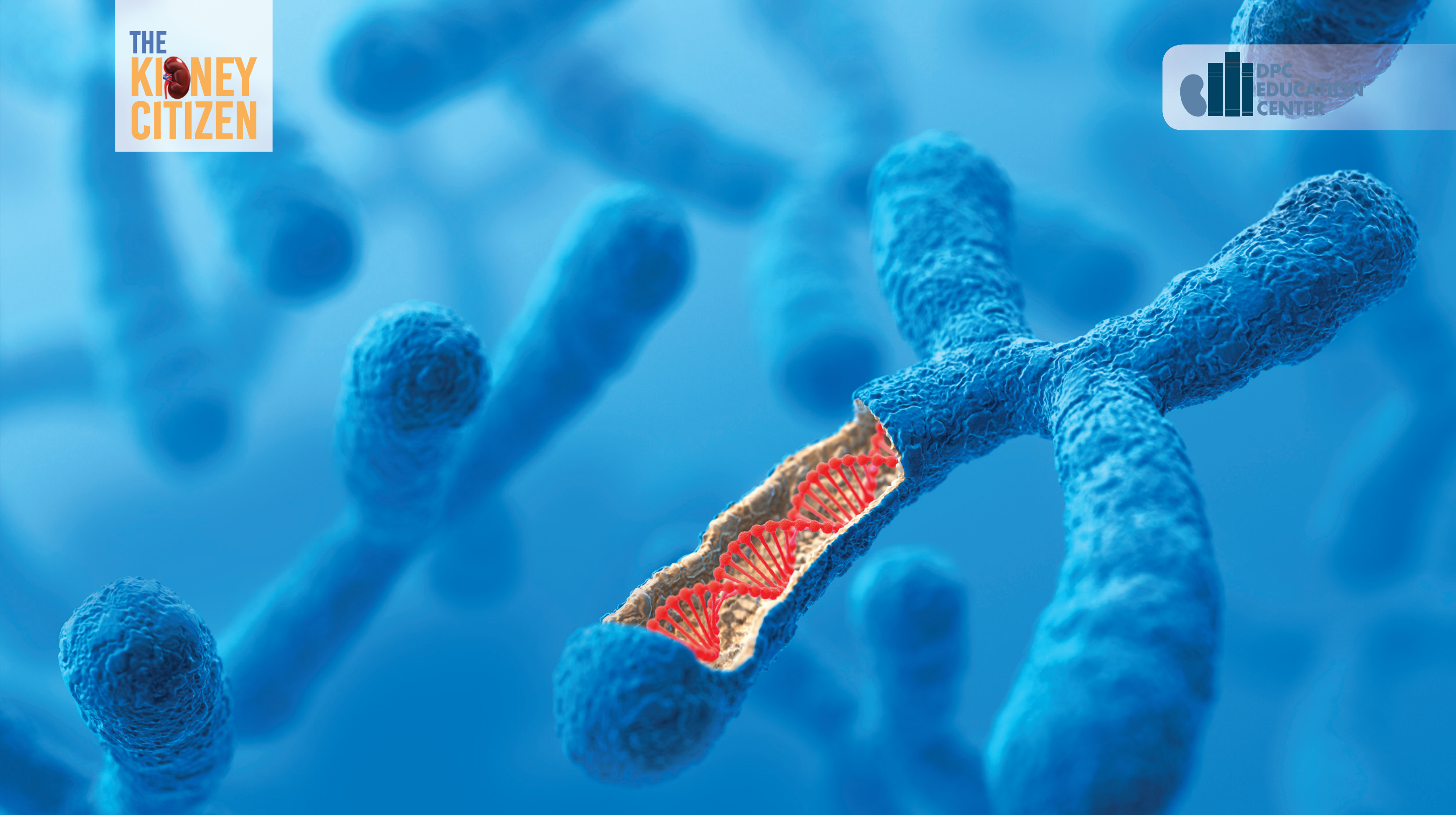
Nancy L. Scott

Nancy L. Scott

DPC Education Center Board
President

THE KIDNEY CITIZEN

DPC EDUCATION CENTER



Kidney Patients Seek Information about Fabry Disease

By **Dawn Jacob Laney**
MS, CGC, CCRC, Instructor/Genetic Counselor at Emory University and
Kathi Niccum, EdD, Education Director, DPC Education Center

What is Fabry Disease?

Fabry disease is an inherited, rare disorder that is caused when a person's GLA gene has changes or mutations that keep it from working correctly. This non-working GLA gene is unable to produce enough of an important enzyme called alpha-galactosidase A whose job it is to break down a fatty substance called globotriaosylceramide or GL3. The GL3 builds up in cells all over the body, in particular in the walls of blood vessels which leads to burning nerve pain in the hands and feet, lack of sweating, fatigue, diarrhea, and eventually damaged organs such as the kidneys, heart, and the brain.

How is it inherited?

The gene that causes Fabry disease is on the X chromosome. Males have one X and one Y chromosome and females have two X chromosomes. When a father has Fabry disease, his only X chromosome has the non-working GLA gene, so all of his female offsprings will inherit the non-working GLA gene and will have Fabry disease. Since Fabry disease only involves the X chromosome and the only way to have a son is for the father to pass on his Y chromosome, male offsprings of a man with Fabry disease will not inherit the non-working GLA gene and will not have Fabry disease.
When a mother has Fabry disease, she has a 50% chance with each pregnancy of passing on the non-working GLA gene to either a son or a daughter,

leading to Fabry disease in that child. In this case both girls and boys would be affected.

Since we know how Fabry runs in families, it is easy to figure out who in the family is at risk for Fabry disease and to have genetic testing performed. Through studies, Fabry experts have found that when one family member is diagnosed with Fabry disease, then an average of five of their relatives will also have the disease. Since there is a FDA approved treatment for Fabry disease and we know the earlier treatment starts, the better it works, it can be helpful to know as early as possible. Some people may not know that testing is available or they may feel guilty, angry or scared of the potential test results, but in this case, knowledge is power. It can be useful to talk to a genetic counselor about testing options and decision about testing for genetic disease. You can learn about genetic counselors and find one near you at: www.aboutgeneticcounselors.com

In order to make it easier for the family members of someone with Fabry disease to get tested, Emory University and the American Association of Kidney Patients (AAKP) have partnered to create the Fabry Disease Family Testing and Education project. Through this project, Emory University offers FREE testing to people who have Fabry in their family and know the change in the GLA which causes the condition. As part of the program, people can also learn more about Fabry disease and available resources. To participate in the testing program people who would like to test for Fabry disease should talk to their doctor and then, the at-risk person can contact directly Emory and order a saliva collection and testing kit by mail. A kit can be ordered by calling the Emory Fabry Center at 404-778-8518 or by emailing Robin Vinson at robin.vinson@emory.edu or Dawn Laney at dawn.laney@emory.edu. In addition to providing the free testing, research from the project has found that family members who have corneal whorls (easily found by any eye doctor), pain in hands/feet, decreased sweating, or a purplish-pink rash in the "bathing trunk area" called angiokeratomas are more likely to have Fabry disease than other family members.

Are Females Affected by Fabry Disease?

Yes, females do have Fabry disease. At one time, it was thought that they were "just" carriers of the disease but did not have any of the symptoms. But now it is known that they can experience symptoms, from mild to severe. Females may not have any or as many symptoms as males because they have two X chromosomes and the one that is working can still produce alpha-galactosidase A. It is important for women to be followed regularly by their doctor even if they have few symptoms since the disease continues throughout life and additional problems may develop.

Do children have symptoms of Fabry Disease?

Yes, children may have symptoms and being a rare disease, it may be difficult to diagnose if no one else in the family has symptoms of Fabry disease. Sometimes children have been told it is "growing pains" when they complain of pain in their hands and feet, cannot tolerate heat, or have GI problems, such as pain after eating, nausea, or diarrhea.

Boys with Fabry disease typically first have symptoms when they are six years old compared to girls who have their first symptoms around eight years old.

However, symptoms have been reported as early as age three years in both genders. Diagnosis of Fabry disease often occurs years after the symptoms have begun.

Children with Fabry disease may have symptoms of kidney problems. According to the Fabry Registry, approximately 15% of boys and girls under the age of 18 years of age have proteinuria defined as a urinary protein: urinary creatinine ratio ≥0.3 or urinary protein levels e0.3g/day. It has been documented that, although rare, children with Fabry disease can experience renal failure as young as 16 years of age. Given the importance of early treatment of Fabry disease, the early detection of this disease has been added to the newborn screening blood test in Missouri and Illinois. Other states are in the process of adding Fabry to their testing as well and some babies in New York City are tested depending on their hospital of birth.

What are ways that the kidneys are affected by Fabry Disease?

According to the Fabry Registry (an international database sponsored by Genzyme that collects information on Fabry disease patients), a number of people with Fabry disease experience kidney problems. Nineteen percent of the females in the Registry had chronic kidney disease, Stage 3 or higher and 2% of them reached End-Stage Renal Disease (ESRD). For males, 34% had chronic kidney disease, Stage 3 or higher and 14% of them reached End-Stage Renal Disease (ESRD).

In addition, heart problems were reported most frequently as a serious problem for males and females. And both males and females in the Registry reported having a lower quality of life after they were in their mid-thirties.

Where can I find more information?

Fabry Support and Information Group (FSIG): www.fabry.org

National Fabry Disease Foundation (NKDF): www.thenfdf.org

ThinkGenetic: www.thinkgenetic.com

Fabry Community (Genzyme): www.fabrycommunity.com

Genzyme Case Managers: 1-800-7454447 (option3)

Fabry Family and Education Testing Project: http://genetics.emory.edu/patient-care/lysosomal-storage-disease-center/lab-testing.html

National Organization for Rare Disorders (NORD): www.rarediseases.org

References

A Guide for Women Living with Fabry Disease 2014. Genzyme Corporation.

Emory University School of Medicine, http://genetics.emory.edu/patient-care/lysosomal-storage-disease-center/lab-testing.html

Fabry Disease & Children 2012.Genzyme Corporation.

Laney DJ, Clynes D. Fabry Family and Education Testing Project. aakpRENALIFE 2016; 6-8.

My Journey with Fabry Disease and Kidney Disease

By **Travis Kelleher**

My mother had been diagnosed with Fabry disease before I was born so I was informed about the condition I had at a very early age. However, that was in the 1970's when information about Fabry was more difficult to find. I feel my childhood was pretty normal for the most part but did come with some obstacles. The first symptoms of Fabry that I noticed were fatigue, burning pain in my hands and feet and anhidrosis (inability to sweat). In grade school, I was picked on often because I could not play very long outside before the fatigue and pain got to be too much for me to handle. Often I lashed out at the "world" as I felt sorry for myself and wondered why I have this condition.

As I learned more about the condition and how to cope with the symptoms, things started to get better. I went on trying to live as normal of a life as I could. When I was in my mid 20's my doctors started to notice my creatinine level begin to rise. Kidney failure is also a symptom

of Fabry. I knew this day would come eventually; I just did everything I could to keep my mind off of it. I made some changes in my life hoping to push off kidney failure as long as I could.

Right about the time I turned 30 I was notified about a clinical study for a new enzyme replacement therapy drug that was being developed for Fabry patients. The study was being held at Mount Sinai Hospital in New York City (NYC). I began to go to NYC from Wisconsin every other weekend to participate in the study which I did over the next several years until the product was approved by the FDA in 2003.

I think being at Mount Sinai had the biggest impact on my life. The clinical study was held in their pediatric department and I met so many young children with a whole assortment of different conditions. It seemed the children with the most severe conditions were the happiest. It was at this time that I realized how foolish I was when I was feeling bad for myself and angry when I was younger. I found out how lucky I had it compared to so many who were/are dealing with a lot worse.

At about this time in my life I had fallen into Stage 3 of kidney disease. With receiving the enzyme replacement therapy, I was hoping to avoid losing my kidneys. In 2008, I met my now wife, Trinh, and we started dating. After I told her about Fabry she really didn't seem to be affected by it, which surprised me. I had noticed my entire life, once I told somebody that I had a rare condition, they didn't seem to stick around very long. Only two months after marrying Trinh, I had dropped into Stage 4 kidney disease and began the process of finding a donor. After family and friends of mine were tested it turned out none of them were a close enough match to be a donor. Trinh went in and was tested in June and it turned out she was a perfect match. We started making plans for surgery expecting for it to occur in late 2012 or early 2013 but I quickly slid into Stage 5, or End-Stage Renal Disease (ESRD), so the transplant surgery took place in July of 2012. I am now four years' post-transplant and things are good. Trinh is still as healthy as can be with no issues. The one bad thing about receiving an organ from your wife is that I now have to agree with whatever she says.

I had once heard, "Every curse comes with a blessing" which I take to heart as I look back over my life. I feel everybody living with a chronic disease will feel that way at some point through their journey with the condition. Fabry disease (and all other health conditions for that matter) is not easy to live with, l but I feel it has made me the person I am today. I am very optimistic and very patient. I have empathy for people who are suffering. I don't sweat the small stuff, plus many more attributes that I really don't know I would have if I didn't grow up with Fabry.

Your Life – Your C

Learn how you can have the best possi

By **Craig R. Fisher**, PhD, MSW, MS, L.C.S.W.,Nephrology Social Worker, The Renal Network, ESRD Network 10

There is a topic I am most passionate about – *It is how to improve our quality of life.*

My goal in this article is to challenge you/ to encourage you to take control of your life - to help you make healthy choices about your treatment and how you live your life. So here goes.

Recently I read a report about two research studies. Between the two studies there were a total of about 6,500 dialysis patients who were split into 3 different groups:

1st group - Patients who made self-directed, choices of modality, i.e. in-center, frequent home hemodialysis, or peritoneal dialysis. Those decisions were based on information they had received;

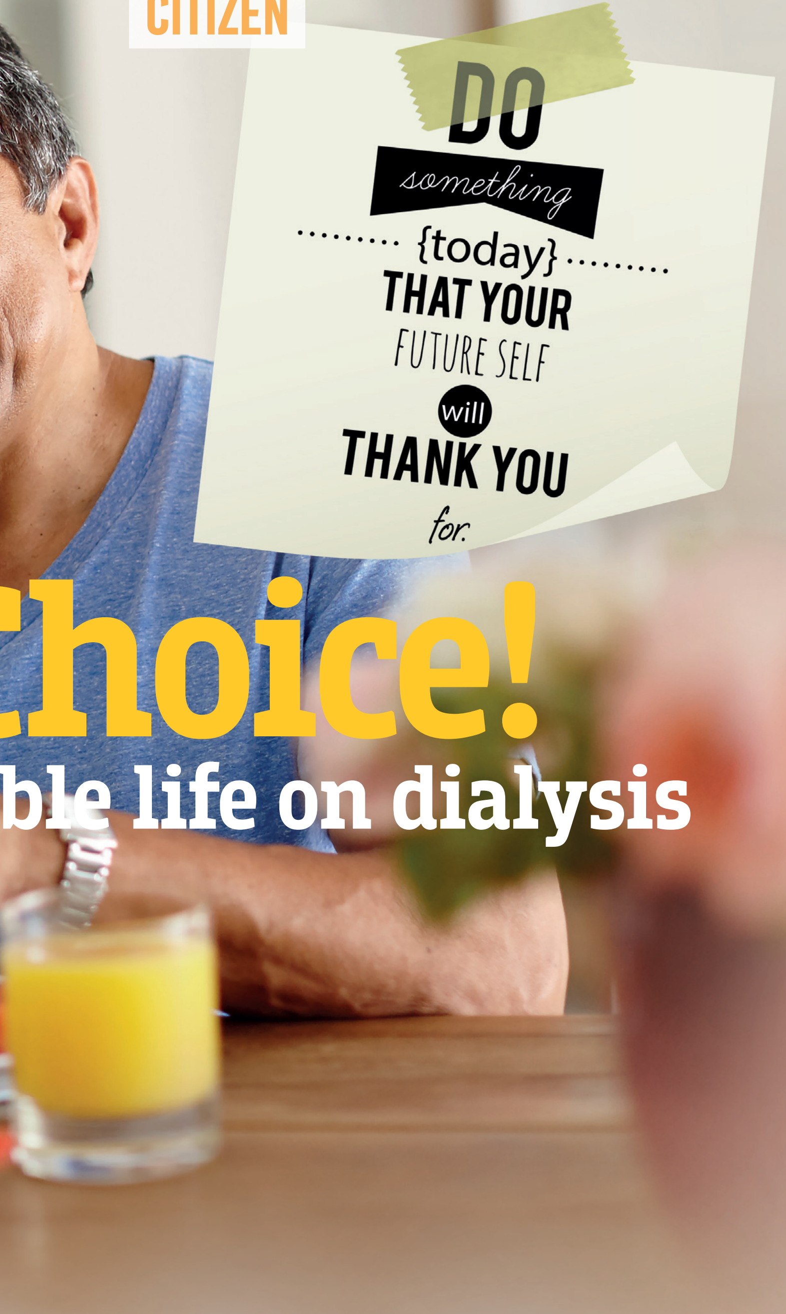
2nd group – Patients who worked with their care team to decide;

3rd group - Patients who allowed their care team to choose for them.

Five years later, the patients who made their own choice (Group 1) were significantly more likely to live longer, healthier, happy lives and to get a transplant. This was true even after ruling out other factors such as age, sex, race, other illness, blood test levels, level of kidney function, education, work, and marital status.

Let me repeat! When self-directed with information, patients who make their own choices live longer, healthier, and happier lives. **This is not JUST some interesting information.** These studies show how important *your* involvement in your treatment is, as well as in the length and quality of your life.

This means that **you can make** choices and that **the**



choice!

ble life on dialysis

choices you make will have a **powerful impact** on your quality and length of life.

One important choice you need to make is on how ***you*** are going to receive your dialysis.

I have had the opportunity to give talks to dialysis professionals about the topic of patient empowerment on a number of occasions. At the beginning of each talk, I ask the same question, “If you were, health wise, able to choose any modality (in-center hemodialysis, home frequent hemodialysis or peritoneal dialysis), how many of you would choose in-center dialysis?” The answer is always the same. In a group of 4 to 500 professionals (I mean doctors, nurses, dietitians, social worker, techs, etc.) I will have only 1 or 2 who raise their hand and say that they would choose in-center treatment.

So, what do the professionals know that leads them to that choice? I am a dialysis social worker of over 18 years and I know why I would choose home treatment.

Let me count some of the whys.

1. I like the idea that I would be in control of when I would do my treatment.
2. Since I would not be locked into in-center treatment days and times, such as (i.e. MWF at 11 a.m., I would be far more able to travel, to choose when I will do my treatment.
3. I would schedule my treatment *around my life* – not my *life around my treatment schedule.*
4. Home patients report feeling stronger, being able to work again and/or do more around the house.
5. Home patients report less restless leg syndrome.
6. They sleep better.
7. They have far fewer and shorter hospital stays.
8. Most patients need fewer medications.
9. There are less diet restrictions.
10. Less stress and higher reported quality of life.
11. ***Again***, they report a higher quality of life.

The life we experience is largely based on the decisions we make or don’t make. The decisions that we postpone making are still decisions. Think about the decisions you have been making and what decisions you can change to new choices.

The goal of this article is to challenge you to become informed, empowered and responsible for your treatment. ***You*** are the patient. ***You*** have the right and ***obligation*** to ask your doctor questions. ***You*** have the right to do research and talk with your treatment team. This is **your** body/your life. ***You*** will live with the consequences of ***your*** choices or **non**-choices.

What are some first steps you can take to making active decisions in your life?

Starting today you can:

Set goals – What quality of life do you want?

Gather evidence and know your options and then begin to make the healthy choices that will help you achieve your goals. You might start by looking into the benefit of home dialysis for you. You are the patient, you have the right to explore your options and if your doctor will not assist you, you have the right to change doctors. However, also remember that as we ask the hard questions, we do this with respect. A gentle word is heard much clearer than an angry shout.

If You Re
Want to
Better!

By **Jim Dineen**

After 25 years as a manager, consultant, salesman, trainer and presenter, Jim's consulting business was starting to flourish. It was then that he was struck with a truly life changing experience, kidney disease. After losing his business, his savings, and almost his life, he realized that his physical health was much more important than he'd ever thought. Jim has seen much in his life and his experiences have given him a unique look at what life can and often does offer. He served with the U.S. Army Infantry in Viet Nam, worked as a manager and leader of people in a successful human resource career, survived three years on dialysis, eight major surgeries, having his abdominal cavity drained over 25 times and a life-saving kidney transplant. He's a husband, father, "papaw" and avid exerciser, writer, author, and professional retiree. Jim knows life and how to tell a story with his own background as reference material. What he knows more than all of this is that everyone has a story and that story should be told. This short story is about how exercise helped save Jim's life.

"If you're looking for that overall, feel good article that solves your problems and cures your ills, including kidney disease, please keep moving. This is probably not the article for you. However, if a little work, a little pain, and the feeling of being on top of the world, in charge of yourself and what is going on with you, is of some interest, stay here. This might be interesting!

Have you ever had one of those days where you just feel like you've been in a gang fight and the gang won? You know, your body aches all over and you're just worn out from everything you've done that day. That's how I feel right now, only I know exactly why my body is hurting this way. My legs are tired, my arms are weak, my chest aches and my back is pounding as though I've been digging ditches all day. I've just come home from the gym and I ache all over. I feel fantastic! You may be wondering if I'm crazy or at least a little wacky. Possibly both but more importantly, I'm like this every day because I do this to myself. I love to exercise!

Kidney disease and its countless complications is a daunting illness to deal with. When I was diagnosed in 1998, I was a pretty active man for my age. At 52, I loved to play racquet ball, golf, run, and take long

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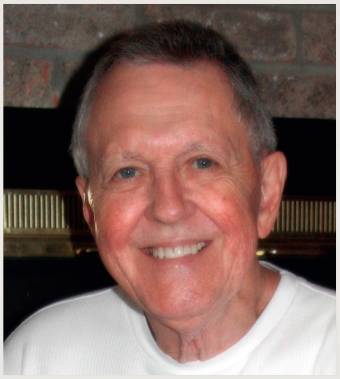
walks and anything else that made me feel alive. My dog and I would walk for miles and then come home to a 30-minute game of catch. I was never a great athlete, but I loved to play the game. Just the thrill of participating was all I really needed. It was always exhilarating and I seemed to respond to physical activity. I have found that this feeling I get from exercise or activity of any kind, would serve me well over the years.



When kidney disease was first thrust upon me it was like a kick in the face. I'm one of those patients who got completely caught off guard by this new challenge. I had no symptoms, wasn't overweight, had never been diagnosed with diabetes and my blood pressure had never been a major problem. I was pretty active and I had actually never heard the term nephrology. Oh, how things can change.

As a new patient, I traveled through all of the emotional and physical stages that any kidney patient experiences; denial, anger, shock and so on. In the first two years following my diagnosis, I went through at least 6 surgeries, gained and lost a minimum 150 pounds of fluid, was informed I had contracted liver disease on top of my kidney problems, had my abdominal cavity drained at least thirty times, lost my ability to walk, and, for about a three-month period of time, would take almost thirty minutes each night to get to my bed on the second floor of my house. Throughout all of this, I reminded myself of everything I'd learned about sports. It really is how you play the game, not if you always win.

My first hurdle was to understand my problem and how it was affecting my body and could continue to affect me. I delved into kidney disease research, learning where it came from and how to get rid of it. That last problem became a big one as I learned you just don't get rid of it. As my understanding increased and my health decreased, I looked back at what had worked for me in the past. What gave me peace? What helped me relax and cope with life's issues? What kept my belief system in order and how did things turn out when I accomplished various milestones? The answer was always exercise.

Early in my illness, my muscle mass was severely impacted by both the disease and the drugs I was taking to control it. I had regularly exercised and could, just prior to my illness, lift weights for an hour and a half and then enjoy a good 30-minute work out on a tread mill. Within seven months of my early treatment regimen, I was lucky to curl soup cans as this was all my arms could handle. I eventually gave up on the lifting completely since I could no longer walk. My muscles atrophied a great deal, and if I got on the floor to play with my dog, it would take me 15-20 minutes to get back up and I usually had to hold on to something to accomplish this. I had to try and I had to believe and so, I did. Soup cans grew to be bean cans that turned into ½ gallons of water. My stairs became my built-in home gym. My wife began to help me learn to walk again, 5-10 feet at a time. It took three months for me to reach a point where I could walk a block from my house and get home again, in an hour.

I ultimately ended up on dialysis and returned to my gym, 3 years after my journey started. I had gone to the same gym for over 6 years and knew everyone there. Nobody recognized me for weeks. I had changed in so many ways. Many fellow patients ask me why I so strongly believe in exercise as part of my regimen and I simply tell them where I was and where I am today. I just celebrated my 13-

year anniversary with my transplant and I go to the gym a minimum of four days a week. I walk at least a mile every day and although I'll never lift the kind of weight I did before, I can do pretty well for my "condition". Someone said age may have some bearing on this, but I try not to factor that into the equation. I might start believing it.

I love sports but I'm not a good spectator. Now, what I mean is I can watch a good football game for only so long or get excited about golf for just short periods and I must do something. There's nothing wrong with my attention span. I just like to participate in life, not watch. It's pretty much the attitude I've followed throughout my challenge with kidney disease. I remember thinking when I was diagnosed that if this disease was going to take anything from me, it wasn't going to be my ability to try or my capacity to believe I could win. I was going to stay in control.

You don't have to be a professional athlete to live and love the benefits of exercise. Maybe your only exercise is walking or running or simply climbing the steps regularly instead of taking an elevator. Swimming is a wonderful exercise if you're fortunate enough to have access to a pool. I strongly encourage you to exercise to the very best of your ability. Talk with your doctor and, if necessary, hire a trainer. Look on the internet or go to the library and find out what will work for you and, whatever it is you find, you will feel better.

Do a little soul searching? Examine your own situation and ask a few questions.

- Would I like to feel better?
- Would I like to look better?
- How would it feel to have less stress in my life, especially related to my illness?
- What physical and mental goals would I like to achieve in the short and long term?
- Do I know my lab numbers and am I willing to track them if I start exercising? Make a log of your weight, blood pressure, cholesterol readings, blood counts, etc. It can be exciting to watch those numbers steadily improve.
- Write down your exercise program and keep track of your progress. Your soup cans can turn into 10 lb. or 20 lb. weights in no time at all. It's not the weight that matters but the progress.
- Ask yourself every day: Am I trying and do I believe exercise is helping me?

When I was a young man, actually just a boy, my parents taught me two important lessons; I can do anything I'm willing to work for and I must believe with all my heart I can do it. When I think about exercise, I remember mom and dad's advice. Until I try something and believe it will work for me, I'll never know the results. This thinking has taken me a long way in my battle with kidney disease. And sometimes a little pain makes life a whole lot more enjoyable.

Most importantly, look in the mirror each morning and ask yourself, "Am I willing to TRY and do I BELIEVE I can do it"? If the answer isn't yes, go find a soup can!

How do you know if you haven't tried?

A Call to Action: The End of the Word "Diet"

Authors: **Molly Phillips**, MPH, MSW; **Barry Smith**, MD, PhD; and **Pamela Hoyt-Hudson**, RN, BSN

Sticking to a diet, especially a kidney diet, is hard. People start diets and break diets. They go back on diets, and then they "cheat." Renal diets can be complex, and many kidney patients are living with multiple health conditions that further complicate what they can, and cannot, eat. The end result is a huge challenge and a likely negative impact on quality of life. Is there anything that can be done about this?

In May 2016, The Rogosin Institute[1] hosted a Roundtable to bring together experts from around the country to talk about the challenges

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[1] The Rogosin Institute is an independent, not-for-profit treatment and research center that has been providing care to patients for over five decades. Rogosin is affiliated with New York-Presbyterian Hospital, Weill Cornell Medical College and is a member of New York-Presbyterian Healthcare System, Kidney Care Partners and the Kidney Care Council. Rogosin provides patient-centered care for individuals with chronic diseases, including kidney disease, diabetes, hypertension, cholesterol or triglyceride disorders, and cancer. Having worked over the past 25 years with health promotion and basic health care in 30 countries around the world, The Institute is uniquely equipped to advance programs that prevent disease and promote good health in underserved communities.

associated with nutrition for Chronic Kidney Disease (CKD) and End-Stage Renal Disease (ESRD) patients and to develop actionable ideas to address these challenges. Roundtable participants included patient activists, healthcare providers, a chef, dietitians, policy experts, scientists, and community organizers[2].

In preparation for the Roundtable, Rogosin staff members interviewed 52 ESRD patients from seven of its dialysis centers in Brooklyn, Manhattan, and Queens. Respondents ranged in age from 21 to 96, were from diverse backgrounds, and had been on dialysis for as little as two months and as long as 21 years. They discussed their experiences with kidney disease, including their food and fluid restrictions, as well as the financial burden of the renal diet. Nearly half (46%) of those surveyed said they did not feel as though they had enough money to spend on food, and 40% receive food stamp benefits. Forty-five percent said that they eat out weekly or more frequently at restaurants ranging from those providing fast food to fine dining. More than two-thirds of respondents read food labels, particularly for sodium, potassium, sugar, and calories, but many shared that it is not always easy to interpret what they are reading. Those surveyed were clear in stating that they wished that they had more educational materials available to them (especially culturally relevant materials), cooking lessons, easier access to healthier foods, financial assistance, and, overall, more support available to them to help manage their illnesses and healthcare needs.

At the Roundtable itself, Dr. Sharon Moe, Director of Nephrology at Indiana University, delivered a keynote speech highlighting the most critical issues in nutrition as they relate to kidney disease, and Rogosin staff members presented the results of the patient interview findings (see above). Following these presentations, a lively discussion involving all participants served to further define the issues and to define actionable projects designed to improve nutrition for kidney patients.

Ultimately, the Roundtable participants agreed that there is a need for a shift in perspective regarding nutrition for patients with kidney disease. There must be a movement away from the word "diet" (generally viewed as meaning restriction) and away from telling people what they cannot eat. Instead the movement must be toward encouraging consumption of GOOD food. As emphasized at the Roundtable by Angela L. Davis, patient activist and President of For Kidney's Sake, Inc., a patient support organization, "We must make good food – and nutrition – cool, fun, funky, and fresh." There must, everyone agreed, be a recognition that nutrition, and good food in particular,

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[2] Roundtable participants included: Paul Conway, American Association of Kidney Patients; Dr. Deidra Crews, Johns Hopkins University School of Medicine; Angela Davis, For Kidneys Sake; Lucas Denton, Melting Pot Foundation; Dr. Orlando Gutierrez, University of Alabama at Birmingham; Oliver Hale, chef; Richard Knight, American Association of Kidney Patients; Dr. Susie Lew, George Washington University; Jarah Meador, US Department of Veterans Affairs; Dr. Sharon Moe, Indiana University School of Medicine; Beth Shanaman, Northwest Kidney Centers; Barry Smith, The Rogosin Institute; Mandy Trolinger, Denver Nephrology; Maggie Veatch, NYC Department of Health and Mental Hygiene; Dr. Daniel Weiner, Tufts Medical Center; Dr. Donald Wesson, Baylor Scott & White Health; and David White, Independent Healthcare Advocate

is an important part of the treatment of renal disease. Put another way, good nutrition is good medicine!

The participants also emphasized the **A, B, C, D's of kidney nutrition health:**

a. Access to affordable, fresh foods
b. Back to basics
c. Cooking, you can do it!
d. Deliver information a patient can understand

In order to create this shift, the consensus of the participants at the meeting was that all health professionals must work side by side with patients at multiple levels and with diverse community groups. Some specifics:

- **At the individual level**, Roundtable participants committed to exploring and endorsing the best tools to help patients manage their illness, their nutritional needs, stress, and the navigation of the healthcare system so that they receive optimal care.
- **At the community and family level**, the commitment was to increase educational efforts and access in both dialysis units and community settings. This includes organizing cooking demos, building partnerships with local community-based organizations that provide ongoing support and even more education, and promoting farmer's markets that can bring fresh, renal-friendly foods to kidney patients and their families.
- **At the academic level**, participants agreed to continue to conduct innovative research, seeking additional funding for research specifically related to kidney health.
- At a **policy level**, participants agreed to develop a list of recommendations for better nutritional standards designed to improve nutrition, healthcare outcomes, and quality of life. Such lists of recommendations and best practices will be used to strengthen advocacy for improved food labeling, as well as enhanced insurance company and government programs (such as, Supplemental Nutrition Assistance Program – SNAP), designed to assist with nutritional therapy and encourage (and make possible) patients' abilities to improve their nutrition.

Changing our approach to nutrition will require the engagement of the entire kidney community – patients, families, friends, providers, researchers, and advocates. Immediate action and ongoing dialogue among all involved is needed. A patient-led nutrition initiative is critical if we are all going to be successful together! The Roundtable participants are anxious to hear from you as to the successes and challenges you face. They also want to hear more about what you think would help kidney patients manage their nutritional needs, and what would help improve access to good, fresh foods in your community. We want to make certain that your voices are heard! Together, we can shift attitudes around nutrition and healthy eating and improve both the quality-of-life and healthcare outcomes for the entire kidney community!

Living Well with Dialysis: Getting the News

By **Barry Hong**, PhD, Chief Psychologist at Barnes-Jewish Hospital and Professor at Washington University School of Medicine in St. Louis, Missouri

It's the news nobody wants to receive. Learning that you need dialysis is never easy. For some people with renal disease, the diagnosis comes abruptly. Others have been living with renal disease for years, waiting for the other shoe to drop. Yet even for those who knew it was coming, it can be disorienting to find out the day has arrived.

The news is often met with a flurry of negative emotions. Fear, shock, anger, grief, anxiety, shame and self-blame are all common reactions. Your mind might be buzzing with worst-case scenarios. That's all normal. Fortunately, the reality isn't usually as bad as people fear. The adjustment takes time, but people can and do live well with dialysis.

One of the best ways to move toward acceptance is to arm yourself with knowledge. The unknown is always scary, so learn about your treatment options and what they entail. Regular appointments at dialysis clinics are no longer the only option for people with renal disease. Some people choose at-home dialysis, and others benefit from a method known as peritoneal ambulatory dialysis. Talk to your healthcare professionals to understand which options best fit your medical needs and lifestyle.

No matter which route you choose, you'll probably find that learning about what to expect helps ease your mind. Many nephrologists offer educational classes or have nurse

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educators to meet with patients. Some match new patients to patient mentors who can help you understand what to expect. Support groups can also help you meet other people who are experiencing the same challenges you're facing.

In the beginning, it's common to feel like you don't fit in with other people receiving dialysis. Even though you've been told you need dialysis, your physical symptoms might not be that bad. You might feel younger or healthier than a lot of the patients you see at the dialysis clinic. When you start, it's easy to feel like you don't belong there.

Sometimes, the feeling you don't belong makes it hard to follow advice from healthcare professionals. It might seem like the information they share doesn't really apply to you. But remember that people come to need dialysis for all sorts of reasons, and from all stages of life. Your situation may be more like others' than you realize. Keep an open mind as you learn from your healthcare providers.

As you start to adjust to dialysis treatment, it's common to experience a kind of "honeymoon period." You might realize that the treatment isn't as bad as you'd feared. You might start to feel better physically. That sense of relief is a welcome one -- but it can be a two-edged sword. After that initial relief, many patients become frustrated by the treatment regimen and the lifestyle changes that go along with it. That setback can be an unwelcome surprise.

So how should you deal with this difficult rollercoaster of emotions? Be kind to yourself. Remember, dialysis is unlike anything you've ever done before. Some days, you might feel like you're coping better than you anticipated. Other days, you might feel like you're not living up to your own expectations for yourself. Once again, these feelings are normal. There's no one "right" way to adapt to your new routine. Take it day by day, and step by step.

Meanwhile, try to preserve as much of your pre-dialysis life as possible. It's easy to give up on hobbies and activities if you feel overwhelmed, but you won't know what you can handle until you try. In the long run, maintaining the activities you enjoy will make it easier to adjust to your new routine.

Experts also say that developing a support network is extremely valuable. Often, people with chronic diseases feel a sense of embarrassment. You might feel like you have a bright light shining on you, when all you really want to do is blend in. But others rarely judge us as harshly as we judge ourselves. So don't be afraid to share your ups and downs with the people closest to you. Your friends and family members probably want to help you, if you'll let them.

The early stages of adjusting to dialysis can be emotional and overwhelming. But with time and patience, many people reach a place of acceptance. By taking these steps to take control of your health, dialysis can help you live a rich and rewarding life.

APA and The DPC Education Center gratefully acknowledge Barry Hong, PhD, Chief Psychologist at Barnes-Jewish Hospital and Professor at Washington University School of Medicine in St. Louis, Missouri, for his assistance with this article

Be Safe: Prevent Bl Infections

By **Kathi Niccum**, EdD, Education Director, DPC Education Center

As a hemodialysis patient, you should be actively involved in your care to help prevent infections. To stay safe from infection, you need to take care of your access, practice good hand hygiene and be watchful that the staff is taking the necessary steps to keep you safe, such as cleaning their hands, when caring for you. Hand hygiene (cleaning one's hands) includes washing the hands with soap and water or using an alcohol-based hand sanitizer. Home hemodialysis patients and their families, as well as peritoneal dialysis patients, need to use good hand hygiene practices at home. Both home patients and dialysis facilities also need to keep the treatment area clean.

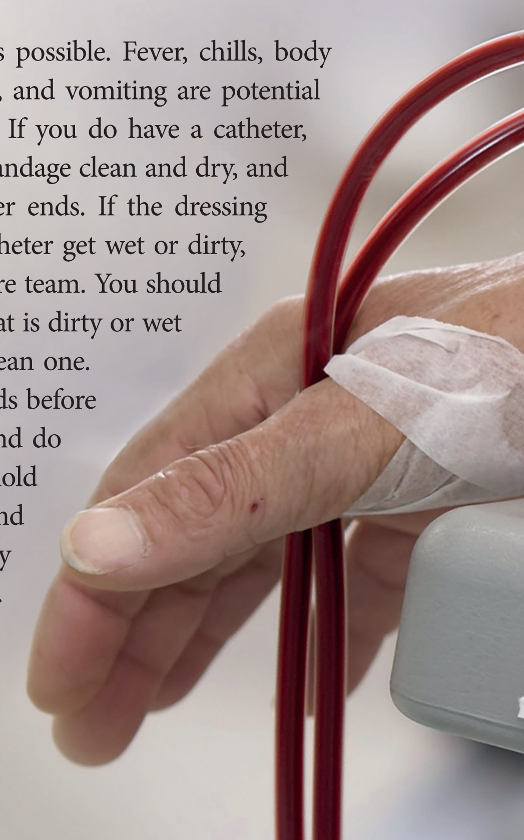
The Centers for Disease Control and Prevention (CDC) has been committed to reducing the risk of bloodstream infections among hemodialysis patients beginning with the creation of evidence-based recommendations to prevent bloodstream infections (BSIs). Several years ago, CDC started the Dialysis Bloodstream Infection (BSI) Prevention Collaborative. Through the Collaborative, the CDC worked with dialysis centers to create a set of core interventions from our recommendations to keep dialysis patients safe from bloodstream infections. The dialysis centers that used these interventions were able to drive down their infection rates. CDC and Collaborative members also created audit tools, checklists, and other materials to help patients and dialysis clinics to protect patients from getting an infection.

More recently, the DPC Education Center has partnered with the *Making Dialysis Safer for Patients Coalition* to help spread awareness and education to prevent bloodstream infections. The Making Dialysis Safer for Patients Coalition is a collaboration of diverse dialysis organizations who have joined forces with the common goal of promoting the use of CDC's core interventions and resources, which prevent bloodstream infections in hemodialysis patients.

"We know bloodstream infections can be prevented when healthcare providers follow CDC recommendations," said Dr. Priti Patel, medical director of the *Making Dialysis Safer for Patients Coalition.* "Patients should be informed and empowered to ask the right questions to make sure they receive safe care. *The Coalition* has developed a guide that can help prepare patients to start a conversation with their healthcare team about what can be done to keep them safe from infections."

A vascular access is your lifeline and is needed for hemodialysis treatments. The access is a surgically created vein that then removes and returns blood during hemodialysis. Both the arteriovenous (AV) fistula and the AV graft can be used long-term for hemodialysis treatment. The fistula is considered the "gold standard" and is the best to have if it is possible. Usually there are fewer infections with a fistula. The venous catheter is usually for short-term use. Catheters have a higher rate of infections than fistulas or grafts. If you are using a catheter for long-term treatment, talk to your healthcare team to learn if you can change to a fistula or a graft. It is important to check your vascular access daily for any sign of infection. If you see redness, pus, tenderness or swelling, tell your healthcare team so they can check it as soon as possible. Fever, chills, body aches, feeling nauseous, and vomiting are potential symptoms of infection. If you do have a catheter, you need to keep the bandage clean and dry, and also protect the catheter ends. If the dressing or the ends of your catheter get wet or dirty, again tell your healthcare team. You should remove any dressing that is dirty or wet and replace it with a clean one.

Do you wash your hands before and after treatment? And do you wear a glove if you hold your access site at the end of treatment? It is very important that you do. Also, ask your staff about the proper way to wash your dialysis



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access and what other steps you and your family can take to help prevent infection.

You, as well as your family and caregivers, should practice good hand hygiene. For example:

- Before preparing or eating food
- Before touching your eyes, nose, or mouth
- Before and after changing wound dressings or bandages
- After using the restroom
- After blowing your nose, coughing, or sneezing
- After touching hospital surfaces such as bed rails, bedside tables, doorknobs, remote controls, or the phone

The Centers for Disease Control and Prevention (CDC) recommends that hands should be cleaned by using soap and water or with an alcohol-based hand sanitizer.

With soap and water:

1. Wet your hands with warm water. Use liquid soap if possible. Apply a nickel- or quarter-sized amount of soap to your hands.
2. Rub your hands together until the soap forms a lather and then rub all over the top of your hands, in between your fingers and the area around and under the fingernails.
3. Continue rubbing your hands for at least 15 seconds. Need a timer? Imagine singing the "Happy Birthday" song twice.
4. Rinse your hands well under running water.
5. Dry your hands using a paper towel if possible. Then use your paper towel to turn off the faucet and to open the door if needed.

With an alcohol-based hand sanitizer:

- Put product on hands and rub hands together
- Cover all surfaces until hands feel dry
- This should take around 20 seconds

If you have concerns that dialysis staff members have not washed their hands, it is fine to ask them respectfully, and to request that they do it again. The staff should wash their hands before touching you, after touching your equipment or anything in your "space" and after they take off their gloves.

You are an important member of your healthcare team. You, your family, and your clinical team can help to prevent infections. Speak up if you have concerns, even if it feels uncomfortable. Do all that you can do to prevent infections – your health depends on it.

To learn more about CDC's Making Dialysis Safer for Patients Coalition and to access free materials to help you stay safe from infection, visit their website: www.cdc.gov/dialysis/coalition

The Benefits of Patient Advocacy: A look into DPC's Patient Ambassador Program

By **Kristy Lukaszewski**, Policy and Communications Director, Dialysis Patient Citizens and Stephen Anderson, Patient Ambassador

Each week, I process Patient Ambassador applications from across the country. Patients have a variety of motivations to join our advocacy network. One common thread among almost all applicants is the desire to help other patients. Stephen Anderson is no exception.

I received his application in September of last year. He answered the questions concisely, he had some experience with public speaking, was a patient network representative and like many others, wanted to help other patients. Stephen was quick to jump into action. He spoke with me a few times on the phone about what an ambassador is expected to do, namely to be our representative in the clinic. He joined our monthly conference calls that provide updates on policy, leadership strategies, and ways to engage with your legislators.

When I first joined the patient ambassador program I was nervous. I wasn't sure what my role would be or how I truly could help patients

across the country from my facility in Indiana. I was soon on conference calls with other patients sharing ideas and learning about the complicated relationship ESRD patients can have with the federal government. The primary issue we have focused on in my time as an ambassador is opening Medicare Advantage enrollment to ESRD patients. Even though I'm fortunate to have secondary coverage, I saw many of my fellow patients struggling to afford the 20% Medicare does not cover. When the opportunity to travel to Washington, D.C. came, I quickly and eagerly applied for a chance to attend.

Each year, our advocacy work culminates with an in-person fly-in. DPC will bring anywhere between 20-30 patients from key states and districts to meet with their legislators in Washington, D.C. Decisions are made based on the advocates work throughout the year as well as their congressional districts. Patients who travel to D.C. have dialysis arranged for them and take part in a day long training where they can network with other patients and healthcare professionals while learning about the issues.

Coming to DC was a whirlwind. I had never done anything like this before. I was excited to meet with other patients to share our experiences on dialysis. After learning more about Medicare Advantage and Care Coordination, we worked in groups to prepare for the next day's meetings. I was paired up with a social worker from Wisconsin, so we were set to have eight visits. It was a very busy day, but as we continued, the meetings got easier and easier. The staff really listened to my story and input as a patient.

The patients in our ambassador program work tirelessly throughout the year, sending messages to their legislators, organizing district meetings, and informing patients in their clinic about the issues that can affect their care.

Going to Washington, D.C. was an eye-opening experience for me. To be heard by my legislators was very powerful. To say it was life changing is not an exaggeration. I remember fondly my experience in D.C. and hope to be selected to attend again.

To join the patient ambassador program, visit http://www.dialysispatients.org/get-involved/patient-ambassadors.

Celebrating Special Days or Holidays

By **Kathi Niccum**, EdD, Education Director, DPC Education Center

Holidays and special days, such as birthdays and anniversaries, occur throughout the year. You may have recently celebrated Thanksgiving and are looking forward to the December holidays.

Initially, though, some people new to or struggling with dialysis may find it challenging to celebrate and to feel the joy of the day. They may worry about how to eat a healthy, kidney-friendly meal if visiting friends or relatives or eating at a restaurant. They may find that they get tired easily and have to figure out how to fit dialysis into their special occasions, especially if they want to travel outside of their community. Holidays are a perfect time for kidney patients to come together and share tips and strategies for overcoming such obstacles and learn how to enjoy the holidays.

This is a great time of year to offer support to those struggling with kidney disease. You can be a resource to other patients. You can encourage those who don't know how they can go out to eat or prepare a special meal to talk to their dietitian, who will have a lot of ideas and tips for them. You can steer someone who wants to travel to the social worker who can help them learn how to arrange dialysis away from home. The social worker will also be able to help with coping skills and relationship concerns. You also may be able to recommend educational resources that were helpful in your kidney journey as well as encouraging them to talk to the members of their healthcare team for more information and suggestions.

Sometimes new patients are having trouble accepting the changes in their lives. You can encourage them to "live in the present moment" and to "let go" of what they could have done differently to either prevent or prolong the start of treatment for kidney failure. You can encourage them to "find the joy" in their lives and to focus on what they can still do (and eat) as opposed to what they need to change. In addition to the religious meaning of some holidays, you may be able to help them see that it is the relationships in our lives that add meaning to the special days. You also may be able to share some tips on how to let others know about their diagnosis of kidney disease or how to "keep the magic alive" in their relationships on anniversaries and Valentine's Day. Your positive attitude and outlook can be contagious and you can be a role model for others as you celebrate the holidays and special events in your life! Enjoy the upcoming holidays!

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