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ESRD Network 10

Renal Outreach

Summer 2017

Thriving Not Just Surviving!

Della Major Named as 2017 Robert Felter Memorial Award Winner

Della Major has been named as the 2017 recipient of the Robert Felter Memorial Award. The Renal Network gives this award each year to a renal patient who has shown outstanding advocacy for renal patients and commitment to improving the quality of their lives.

For the Network, Della serves as a member of the Patient Advisory Committee (PAC), is a Facility Peer Representative at her dialysis facility, and also serves on the NCC Mental Health, Grievance, and HAI Affinity Groups, national patient committees for all of the 18 ESRD Networks. She also volunteers for the National Kidney Foundation of Illinois, is Patient Ambassador for Dialysis Patient Citizen, organizes monthly lobby days for her dialysis facility, and volunteers at her church and at a local food pantry.

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This newsletter, *Renal Outreach*, is one way patients can stay up to date on Network activities and projects. *Renal Outreach* is free of charge. To subscribe, call the Network at 1(800) 456-6919 and ask for Katie Stark. Or visit www.therenalnetwork.org

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"From my first treatment, I decided to define what my new normal was going to be," Della stated on her application for the award. "As an educator, I always believe that knowledge is power. My first goal was to educate myself about kidney disease and the effects it will have on my life. I would research continually on the internet to map out a plan and guideline for myself on living with kidney disease.

"My second goal was established when I was asked by my dietitian to write an article for The Renal Network about living with kidney disease. At first, I was unsure but afterwards, it ignited a fire within me to share my story to all, and to advocate for others and bring awareness about kidney disease," she said.

"My will to live is stronger than this disease."

"My third change occurred with my eating habits. From my research, I have learned that establishing good eating habits helps my body to be stronger and function better. By incorporating exercises and good nutrition into my life, I am able to have the energy I need to continue my passion to advocate, educate, and encourage others to get involved both at a national and local level in my state. My motto is thriving not just surviving."

Della was nominated for the award by staff members in her dialysis facility.

"I have watched her push forward through various levels of adversity each day to become an active member in the renal community," said Danielle Crowder, social worker at Della's dialysis center. "Della is an educator to her core, so she educated herself about ESRD and dialysis. Della has also experienced different modalities of dialysis treatment such as in center, home hemodialysis and nocturnal dialysis. As a result, Della has become an outstanding advocate for herself and her peers."

"Della takes all her volunteer positions very seriously and reaches out to other patients to share the resources available and to help improve the quality of their lives," said Mary Ellen Brabec, dietitian at Della's dialysis unit. "Della brings a wealth of experience as a patient in the position of Facility Peer Representative. She understands what it is like to work full time and be on dialysis… her perspective enriches her ability to interact with other patients in our unit and in the area." As the 2017 Felter Award winner, Della will represent The Renal Network at the national meeting of the American Association of Kidney Patients, and write an article about her experience for a future newsletter.

ICH CAHPS Survey

What is it?

ICH CAHPS (said like "ICH caps") Survey stands for the In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems Survey. You might also see it shortened to the Medicare In-Center Hemodialysis Survey.

Who is it for?

The ICH CAHPS Survey asks adults with kidney disease about their patient experiences with care from their dialysis facility.

How is it provided?

A survey company (not your dialysis facility) approved by Medicare may contact you either by phone or by mailing you a paper copy. Patients are selected randomly.

Why is it important to take the survey?

If you are randomly selected, this is your chance to share about your dialysis experience and make it count. All individual responses are kept private and are never linked back to your name. The overall facility results are used in a few ways:

1. Dialysis staff use the results to measure the quality of their patients' experiences and look for opportunities to do better.
2. Centers for Medicare & Medicaid Services (CMS) use the results to monitor dialysis facility performance.
3. Results are made public for patients to be able to view online and see how different facilities score compared to others.

Grievance Corner

for relevant information to help your voice be heard…

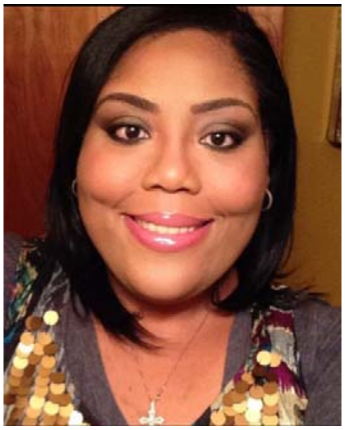
Caprisheus Barbee is Director of Patient Services for The Renal Network

Did you know there was a patient-created resource to help walk you through the grievance process if/when you need it, and is available in both English and Spanish? It's called the ***Dialysis Patient Grievance Toolkit*** and the resource can be found on this webpage:

http://esrdnetworks.org/resources/toolkits/patient-toolkits/dialysis-patient-grievance-toolkit-1

Living with kidney disease can be both scary and challenging, so if concerns or issues related to your dialysis services and treatments occur there is a formal process to help address them. The website above, the clinic or program social worker, and The Renal Network are all resources that are available to help you navigate the grievance process. No matter how small or large your concern may be, talking to someone at your clinic is the ***first*** step toward solving it and serves as an opportunity to improve patient-centered care services for the dialysis community. **Chapter 7 of the grievance resource shares the role of the Network in the grievance process**. If you have not already reviewed the ***Dialysis Patient Grievance Toolkit***, you should. If you need assistance finding access to this or any of the resources on our website, or if you would like information on filing a grievance, please contact Caprisheus Barbee at the Network office, (800) 456-6919.

Do You Have What It Takes to be a Facility Peer...We Think You Do!



By Quin Taylor
Patient Liaison & Kidney Transplant Patient

Could you become a Facility Peer and help patients at your dialysis unit? We think you can!

The Network sponsors the Facility Peer Program, where patients can help out dialysis facility staff members by talking with other patients about common concerns. Facility Peers also help distribute education information to patients.

Each facility that joins the program recruits a staff member to act as the Facility Staff Coordinator and at least one patient Peer Representative to help spread the word.

We've designed this program to be low impact on your time yet high impact to benefit patients.

The program is currently operating in many dialysis facilities within our Network with great success. Benefits include:

- Access to free monthly educational webinars and educational resources to increase patient understanding about improving their quality of life and care.
- Patients taking an active role in their care, which can lead to improved medication and treatment adherence, communicating more effectively with staff, and participating in care plan meetings.

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- Peer support (provided through the Facility Peer Program) that encourages patients to make their care a priority, confirm they still have independence and give hope not only to the patients but the family and friends that support them.

- Tools provided through this program help to enhance communication between staff and patients, which can lead to fewer conflicts.

- Access to The Renal Network for individual assistance and resources that Facility Peer Representatives can immediately implement.

If you would like to learn more information please check out our page on www.therenalnetwork.org under Patient Services. You can download the Facility Peer Program handbook to become oriented to the program. If you have any questions, please reach out to me, Quin Taylor, Patient Liaison, at qtaylor@nw10.esrd.net or (317)735-3558.

Winter is Coming. Are You Prepared?

Summer is winding down, autumn is close at hand…then winter sets in! Are you prepared for winter and all the storms and the emergencies the season can bring: piles of snow, ice storms, power outages, you name it.

No use in despair, just be prepared! Emergencies can actually happen any day of the year in any season. A little preparation will go a long way to help you meet these situations.

The Kidney Coalition for Emergency Response (KCER) has a wealth of information to help you prepare for many emergencies. Check out the webpage at http://www.kcercoalition.com/en/resources/patient-resources/

There you will find information on how to prepare, such as:

- Preparing for Emergencies: A Guide for People on Dialysis
- Developing a Family Communications Plan
- Planning for a 3-Day Emergency Kidney Diet
- Patient ID Cards for Use in an Emergency
- Save a Life Fact Sheet

This, and many other materials, are also available in Spanish.

So stop by the KCER website, and also check in with your dialysis facility to be sure you are up to date on any emergency planning that's being done by your dialysis clinic.

He has her heart, and now her kidney!

By Michelle Sides, CHT

Living Kidney Donor & Dialysis Technician

I will start out with a little background for you. My name is Michelle Sides and I am a living kidney donor, and my husband, Mark, is the transplant recipient. Mark was diagnosed with kidney disease in 1987 after leaving the Marine Corps. We were married on August 11, 2001 and became a family of eight, six kids and us.

I had worked in healthcare most of my career, mainly doing in-home care. In 2008, I decided to change my career options. The local community college had just started a Certified Hemodialysis Technician course. I knew right away that this is what I wanted to do, largely in part to better understand what Mark was going through and what the future may hold. I completed the course and was hired by our local dialysis unit. On March 11, 2010 I took the Board of Nephrology Examiners Nursing and Technology test and just a few days later I received my letter stating that I had passed and was officially a Certified Hemodialysis Technician. I still work as a CHT.

As our story unfolds, Mark's kidney function was declining. I had always said, "When the time comes, I will just give you one of mine." Knowing that it isn't just that easy - I mean, really, what are the chances we would be that lucky for me to be a match? As a back-up plan we discussed home options.

In June of 2014 Mark's kidney function had decreased. Good days and bad days were turning in to good mornings and bad afternoons. He had been sick for so long he had forgotten what it really felt like to feel good. The time had come. We would soon be faced with some tough decisions. Dialysis was getting closer. I knew immediately I want to be tested to see if I was a match. I had made a promise to him and I was going to keep it.

His nephrologists agreed that transplant was option and we went for testing. We agreed on a transplant center and the evaluation process was scheduled. As time went by it all became so real! Then, on July 3, 2014, I received a call from our transplant coordinator. The test results were back. I was a match. Did I mention, Mark's 50th Birthday was July 4th, the day after I received the phone call? I had big plans to reveal that I was going to give him something better than any birthday present I had ever been able to give to him in the past. I just had to wait one day to tell him.

Well that didn't happen. Mark came home and immediately asked me what was wrong. I clearly was a little emotional from the news. I said "sit down I have something to tell you." I'm pretty sure it went something like: I received a phone call today. I'm a match. When it sunk in we just held each other and cried tears of joy. Happy Birthday! You are going to be the new owner of a used, but good, kidney.

We were able to go ahead in September and schedule the transplant. Part of the great thing about having a living donor is you have more flexibility and time to get your affairs in order. I would need to give my work notice of my leave and we would need to get our finances in order.

The transplant was set for October 16, 2014. Surgery went well. Mark's new kidney immediately started working. Even though he had just gone through major surgery he was feeling great and couldn't believe how much better he felt. He said it was if a film had been lifted, his thinking was clearer, and he felt good.

Today we both are doing great. We are so grateful for all of the joys in our life. Since the transplant, Mark has been able to experience life events such as grandchildren being born (we are now up to nine), his son's wedding, and a special fishing trip with his grade school buddies. Last year we took a vacation to Florida and celebrated our 15th wedding anniversary. Most recently he was able to celebrate my parent's 50th wedding anniversary this past April.

With all of that being said, thing are not always great. We have had some bumps in the road and some challenges related to the transplant. Rejection scares can be a very emotional road. Having a transplant is a big responsibility and takes a good support system. It is not a cure, but it is what has allowed my husband to maintain and have some normality in his life, simple things many of us take for granted every day.

August: A great time to get vaccinated!

Vaccines protect you all year round, but August is a great time to get vaccinated.
In August, as summer winds down, it's a good time for you and your family to make plans to get the flu vaccine. The vaccine usually becomes available in mid- to late-August. Getting the vaccine early can help prevent you and your family members from getting the flu throughout all of flu season. You can learn more about the flu and flu vaccine by checking out the website https://www.cdc.gov/flu/

Additionally, dialysis patients should make any extra effort to get not only their flu vaccines, but also be sure they are vaccinated against pneumococcal pneumonia and hepatitis B. These are serious diseases that can largely be prevented through vaccination. As a dialysis patient, it's important for you to be vaccinated to protect your immune system, which is weakened by kidney disease.

If you have questions, just ask your nurse or technician for more information on vaccination, many may be available at your dialysis clinic.

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The Renal Outreach is a publication by The Renal Network and is a newsletter for individuals and their families living with chronic kidney disease. The Renal Network works to facilitate the achievement of optimal wellness for renal disease patients, including those on dialysis or who have received a kidney transplant.

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The Renal Network is Tweeting!

The Renal Network has joined Twitter! You can find us @RenalNetwork. If you want to join us, you can download the Twitter app on your smartphone and create an account. No smart phone or cell phone? No problem! You can go to www.twitter.com and create an account so you can tweet us. Don't forget to mention us so we can retweet you! See you in the Twitterverse!

Contact Us

Give us a call for more information about our services and resources.

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Visit us on the web at
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