Summer 2018

PATIENT

A Quality Insights Renal Network 5 Newsletter

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Active People Just Like You!

Meet Maria! She has been an in-center hemodialysis patient for 23 years. While she does not currently selfcannulate, she did in the past. Recently, she asked for additional training. With this training, she plans to begin again. When Maria first started dialysis, her facility administrator (FA) saw how eager she was to learn. Maria has a passion for challenges. She is also a fast learner. This combination of skills set the perfect opportunity for Maria to share her knowledge with other patents. With some additional training, Maria's FA created a position for her as a set-up technician.



This position allowed her to assist with the cannulation of other patients. Through this experience, Maria gained a stronger sense of purpose. It also created a teaching environment within the clinic.

This paved the way for Maria to become one of the Network's Patient Advisory Council (PAC) members. Maria shares that by being a part of the PAC, she feels she is a part of something important. "PAC gives me the opportunity to meet so many people and learn so much. ESRD is so different all over the world from healthcare to in-center and home dialysis. We get to share our opinions and feel good being listened to." (*Continued on page 2*)

Quality Insights Renal Network 5

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Improving Patient Engagement in Your Clinic

"Patient engagement is the respectful, welcomed, and valued involvement of the patient, including their family as requested, in every aspect of medical care, in order to achieve the highest quality and best possible health outcomes for the patient." - QIRN-5 Board of Directors, 2013.

There are many ways for patients to become more engaged in their dialysis treatments. In this issue, we will explore three different topics to help you get started.

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- Share this information with your peers and encourage them to participate, too.
- If you don't have access to a computer, ask your dialysis team to print online information you see here.
- Ask your facility what Network projects they are enrolled in, and offer to help.
- It's all about
 Patient
 Engagement!! Join
 a support group,
 become a Peer
 Mentor, be more
 active in your self care!

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Currently, Maria is in school for Contemporary Office Technology. She hopes to work in healthcare. In addition to being a member of the PAC, Maria also participates in the Blood Stream Infection (BSI) project with the Network. She enjoys being able to share information from the Network with other dialysis patients. Maria believes the more knowledge you have the better you are at being able to advocate for yourself.

Support Groups

Support groups are a great way to bring dialysis patients and their families together. When patients participate in support groups, they create bonds with others just like them. Hear what one of our very own subject matter experts has to say about his experience with his own support group:

"We are a very close knit group seeking to find a solution to kidney disease. We encourage, motivate and empower each other to fight against any stigmatism that comes with this disease. We have tackled attempted suicide, depression, anxiety, self-imposed solitude, abandonment, relationship and dating while on dialysis and caregivers/partner concerns and issues. We have mourned the loss of members together as well as celebrated members whom have been transplanted. To me, this is a safe haven for those suffering the same fate to come and share in the family experience." - Patrick Gee, PhD, JLC (SME and PAC Member)

The Network is currently working on developing a list of support groups throughout the region. We will make this information available as soon as possible.

Peer Mentors

Peer Mentors are a great way to improve patient engagement. It provides a sense of purpose for both mentors and mentees. It also increases ESRD knowledge for both. The more knowledge patients have, the more confident they become. As a result, depression symptoms are significantly decreased. Some other benefits of peer mentors include:

- Improved self-motivation
- Increased social support
- Improved dialysis social support
- Fewer missed appointments
- Better self-management of dialysis symptoms

In 2015, a PEER UP! Pilot program was developed that focused on the benefits of peer mentors within the dialysis clinic. To learn more about the value of peer mentors, please visit our website by following the link provided below. This link will also provide you with a valuable toolkit from the PEER UP! Program: <u>https:// www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program/</u> <u>Background-Overview.aspx</u>

Self-Care Strategies

One of the most empowering steps a dialysis patient can take is to practice self-care strategies. A number of studies prove that patients who are more actively involved with their dialysis care have better selfesteem. Clinical outcomes also improved. When you participate in your own treatment, you take control of your healthcare.

Some examples of self-care strategies include:

- weighing yourself
- self-cannulating
- washing and holding your access site
- r helping to set up your machine & measure your vital signs
- administering some of your medications
- collecting some of your labs

For more information on how to incorporate self-care strategies into your dialysis regimen, please visit this helpful resource we found from DaVita: <u>https://www.davita.com/kidney-disease/dialysis/treatment-</u><u>options/in-center-self-care-hemodialysis/e/5275</u></u>

Social Media



Follow us on Twitter at @kp_mar



Like us on Facebook at Kidney Patients of the Mid-Atlantic Region



Grievances

The Network is available to handle patient concerns. To file a grievance, please contact Quality Insights Renal Network 5 at

Patient Toll-Free Phone: 1-866-651-6272

Email: <u>qirn5@nw5.esrd.net</u>

Mail: 300 Arboretum Pl. Suite 310 Richmond, VA 23236

Web: www.esrdnet5.org



Resources to the Rescue!

- NKF Peers 1-855-NKF-PEERS

 (<u>https://www.kidney.org/patients/peers</u>) Online and
 telephone support through the National Kidney Foundation
- AAKP offers information on Support Groups. You can search by state. Additional groups can be added. (<u>https://aakp.org/support-groups/</u>)
- Renal Support Network (<u>https://www.rsnhope.org/</u>). Access to the Hopeline– a peer support hotline and more.

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