

# PATIENT



# Insights

A Quality Insights Renal Network 5 Newsletter



Quality  
Insights

Renal Network 5

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## Active People Just Like You!

Meet Nieltje Gedney. She has been doing home hemodialysis alone for five years, and she self-cannulates! This treatment modality has helped her stay busy with all of her activities, such as advocating with Home Dialyzors United, being an AAKP Ambassador, informing the Kidney Health Initiative, serving on the Advisory Board for The Kidney Project, contributing blog posts to Home Dialysis Central, and participating as a subject matter expert (SME) with the Network.



As an SME, Nieltje provides the patient perspective on the Network's Home Dialysis and the Gainful Employment projects. In these projects, dialysis facilities are guided through improvement efforts by the Network. Patient subject matter experts help the facilities to see how this work impacts their patients and what is important to them. These groups are also brought together across the nation with CMS to share best practices. "What I find most meaningful is the coordination between clinics and CMS—helps to see what's going on out there!"

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## Back to School

Sometimes rehabilitation means continuing education or returning to school to learn a new profession. Some scholarship programs exist for dialysis patients, transplant recipients, and their families. Check Google using the search words "dialysis scholarship." Check with local colleges for assistance in identifying grants and financial aid for minorities, people with disabilities, and special fields of study. Visit <http://www.esrdnet5.org/Patients-Families/Education-Resources/Vocational-Rehabilitation/Schooling.aspx> for more resources.



- ↳ *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.*
- ↳ *Become a Subject Matter Expert (SME) with the Network, and work with others to help facilities understand the patient perspective!*

## People Like You

*(Continued from page 1)*

The goal of the Gainful Employment project is to increase access to and use of employment services in the community by people on dialysis. Nieltje has accessed resources from her local vocational rehabilitation office on a couple occasions. "While not all voc rehab offices are created equal, they can be a valuable resource to dialysis patients, especially if you are working at the time you start dialysis. They can help re-train and/or re-educate you for jobs that will accommodate your disability and work around your dialysis treatment. Maintaining some type of employment is important, not only economically but also to maintain a positive psychological sense of self worth." She points out that even if you can't work, volunteering will still contribute to an overall feeling of self-worth.

The goal of the Home Dialysis project is to increase the number of people starting to train for a home modality. Nieltje has been doing home hemodialysis alone for five years, and she self-cannulates! As a busy, independent woman, this was the best choice for her. "Home dialysis makes it easier to do treatment on your schedule and not a clinic's set time—which may have nothing to do with what is important to you!" She firmly pronounces everywhere she goes that home dialysis has been shown to provide outcomes equal to or better than cadaver transplants.

"Dialysis is a game changer, but you can still live a 'new normal' life. What will keep you healthier is taking control of your life, owning your illness and your treatment, and not checking your independence at the door of the clinic. An educated patient is a healthy patient!"

## Become a Subject Matter Expert!

- ↳ *Participate on Network project calls.*
- ↳ *Review and develop educational materials/events.*
- ↳ *Evaluate actions taken in a project to improve quality.*
- ↳ *Share ideas and concerns to enhance learning for all.*
- ↳ *Work with others just like you!*

## Back in the Saddle Again

Having chronic kidney disease has changed your life, but there are things you can do to reduce the impact on your lifestyle and income. With the exception of heavy physical labor, most patients are capable of performing the job tasks they did before they started dialysis. You may even choose to pursue a new dream! Here are some tips for getting started:

- ☞ **Talk with the social worker** about your goals for employment, school, volunteering, hobbies, and increased social or physical activities.
- ☞ **Contact a Work Incentives Planning & Assistance (WIPA) Organization** near you. Call 866-968-7842 or go to <https://choosework.ssa.gov/findhelp/>. WIPA can:
  - ☞ Answer your questions about how part-time, full-time, or seasonal work would affect your individual disability benefits and other benefits you may receive from Federal, state, and local programs.
  - ☞ Respond to your questions about how work would affect your health care.
  - ☞ Discuss your individual goals, including possible barriers and the resources or services you would need to overcome those barriers.
  - ☞ Help you plan how to use work incentives or other benefits for a successful return to work.
- ☞ **Attend a National Work Incentive Seminar Event (WISE)** or webinar. To locate events or to listen to previously recorded sessions, go to <http://www.socialsecurity.gov/webinars-tutorials/index.html>.
- ☞ **Call Ticket to Work** (help returning to work) at 866-968-7842, or [www.yourtickettowork.com](http://www.yourtickettowork.com).
- ☞ **Visit the Department of Labor’s Career One Stop website** for tools to help job seekers and students: <http://www.careeronestop.org/>.
- ☞ Contact the vocational rehabilitation (VR) office in your area, and ask about its application process.

### Find your local VR office

District of Columbia	202-442-8400	<a href="http://www.dds.dc.gov">www.dds.dc.gov</a>
Maryland	888-554-0334	<a href="http://www.dors.state.md.us">www.dors.state.md.us</a>
Virginia	800-552-5019	<a href="http://www.vadrs.org">www.vadrs.org</a>
West Virginia	800-642-8207	<a href="http://www.wvdrs.org">www.wvdrs.org</a>

## Social Media



Follow us on Twitter  
at @kp\_mar



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



## Grievances

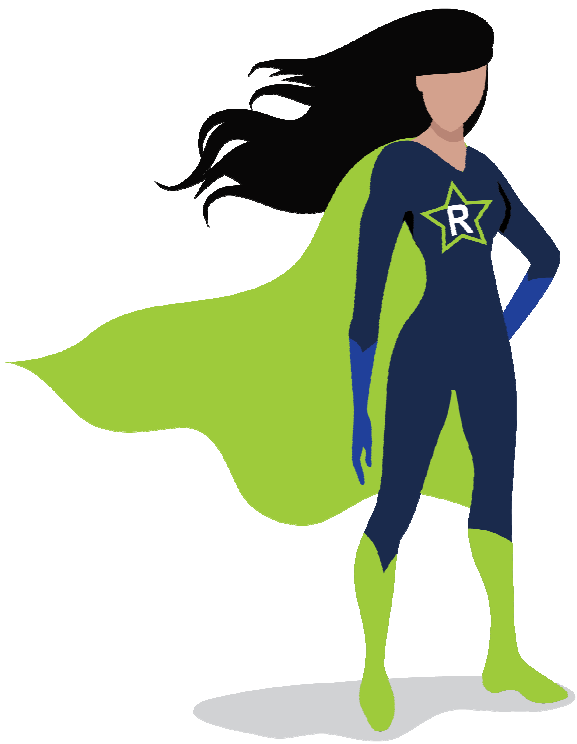
The Network is available to handle patient concerns. To file a grievance, please contact Quality Insights Renal Network 5 at

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

Email:  
[qirn5@nw5.esrd.net](mailto:qirn5@nw5.esrd.net)

Mail: 300 Arboretum Pl.  
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Richmond, VA 23236

Web: [www.esrdnet5.org](http://www.esrdnet5.org)



## Resources to the Rescue!

- ☞ **Patient Services Brochure** (<http://www.esrdnet5.org/Files/Pt-Education-Resources/PtLiaisonBooklet2016.aspx>) Describes the role of the Patient Liaison
- ☞ **Life Options** ([www.lifeoptions.org](http://www.lifeoptions.org)) This website has resources related to optimizing your quality of life, including the booklet *Employment: A Kidney Patient's Guide to Working and Paying for Treatment*
- ☞ **National Kidney Foundation** ([www.kidney.org](http://www.kidney.org)) This website has resources on a variety of topics related to kidney disease, including *Working with Chronic Kidney Disease*

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