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## Cleanliness in the Clinic: How Speaking Up Can Prevent Infection

As told by Dawn Edwards, New York City, NY.

My name is Dawn Edwards, and I live in Queens, New York with my mother and 27-year-old daughter. I have been living with kidney failure and receiving dialysis for 25 years. I am a retired Post Office worker and currently work for Next Stage Dialysis as a patient advocate in community outreach. I am also a Patient Advisory Committee (PAC) Advisor for the IPRO End-Stage Renal Disease (ESRD) Network of New York and a national Subject Matter Expert (SME) for the ESRD Network National Coordinating Center (NCC). I have been an involved patient advocate for 23 years.

During my 25 years on dialysis, I have had many infections. I have come to accept infections as part of my treatment because I have a catheter. Having a catheter makes me very vulnerable to bacteria caused infections. I use a catheter because I ran out of areas on my body to create a dialysis access. I have been on various types of treatments for so long, I ran out of places to put any more accesses! In 2010, I got Methicillin-Resistant Staphylococcus Aureus (MRSA) that I contracted once I returned to in-center dialysis after a failed transplant. This was the worst infection I have had. My infection affected not only my own life, but also the lives of my family members. I was unconscious for weeks putting incredible pressure on my mother, my daughter, and my church family. This is what drives my passion for infection prevention; infection affects not only the quality of life for the patient, but for those who love the patient as well.

Aside from MRSA, my other infections have been minor and easily resolved with antibiotics. I have since chosen to use a catheter, which allows me to do nocturnal dialysis from home. Having a catheter made it very hard to find a dialysis facility that would let me do at-home treatment. By holding myself accountable for my own treatments, I didn't worry as much about infections. By being in charge of my own treatments, I am in control of how hygienic I am. People on dialysis are like germ sponges, because of the lowered immune system of that comes with kidney failure. It is our responsibility to make sure we do not contribute to the spread of infections and disease and that we work with our fellow patients and healthcare team to ensure that they are being clean too!

Taking responsibility can take many forms. It may mean learning how to wash your hands and access before sitting down in your seat, reminding other patients to wash their hands before sitting down, speaking up when you notice your healthcare team neglecting to wash/rub their hands or follow aseptic procedure. There is no need to be confrontational or rude to give other patients and healthcare team members a friendly reminder and there is no such thing as being ashamed to ask for cleanliness. No one should be ashamed to ask for safety and a better quality of life!



If you have a concern, but you are uncomfortable talking to a facility staff member, you may call your ESRD Network at:

**IPRO End-Stage Renal Disease Network of New England (CT, MA, NH, RI, VT)**  
1952 Whitney Avenue, 2nd Floor  
Hamden, CT 06517  
Patient Toll-Free:  
1 (866) 286-ESRD (3773)  
Fax: (203) 389-9902  
E-mail: [esrdnetwork1@ipro.us](mailto:esrdnetwork1@ipro.us)  
Web: [network1.esrd.ipro.org](http://network1.esrd.ipro.org)

**IPRO End-Stage Renal Disease Network of New York**  
1979 Marcus Avenue, Lake Success, NY 11042  
Patient Toll-Free: 1 (800) 238-3773  
Fax: (516) 326-8929  
E-mail: [esrdnetwork2@ipro.us](mailto:esrdnetwork2@ipro.us)  
Web: [network2.esrd.ipro.org](http://network2.esrd.ipro.org)

**IPRO End-Stage Renal Disease Network of the South Atlantic (GA, NC, SC)**  
606 Aviation Parkway, Suite 30  
Morrisville, NC 27560  
Patient Toll-Free: 1 (800) 524-7139  
Fax: (919) 388-9637  
E-mail: [esrdnetwork6@ipro.us](mailto:esrdnetwork6@ipro.us)  
Web: [network6.esrd.ipro.org](http://network6.esrd.ipro.org)

**IPRO End-Stage Renal Disease Network of the Ohio River Valley (IN, KY, OH)**  
3201 Enterprise Parkway, Suite 210  
Beachwood, OH 44122  
Patient Toll-Free: 1 (844) 819-3010  
Fax: (216) 593-0101  
E-mail: [esrdnetwork9@ipro.us](mailto:esrdnetwork9@ipro.us)  
Web: [network9.esrd.ipro.org](http://network9.esrd.ipro.org)

The Network will accept grievances by phone, fax, email or postal mail.

### Tips for Speaking Up:

- Think logically - Don't behave emotionally when asking about hand washing compliance. Identify your discomfort then prepare to speak.
- Show respect - Affirm your respect for doctor or nurse's competence to help set the stage for positive dialogue
- End with a question - Reiterate you are interested in their professional point of view. End with "Is this correct?" or "Do you see why I am worried?"

\*These tips are based on:

<http://www.foxbusiness.com/features/2013/10/25/why-need-to-ask-doctors-if-theyve-washed-their-hands.html>

### Additional Resources

- **National Kidney Foundation (NKF)**  
[www.kidney.org/kidneydisease/communicate-healthcare-team](http://www.kidney.org/kidneydisease/communicate-healthcare-team)  
NKF has a webpage dedicated to communicating with your healthcare team
- **American Association of Kidney Patients (AAKP)**  
[www.aakp.org](http://www.aakp.org)  
AAKP has many resources on line and an annual in person convention. (813) 636-8100 Toll-free: (800) 749-2257  
E-mail: [info@aakp.org](mailto:info@aakp.org)
- **Renal Support Network (RSN)** Website: [www.RSNhope.org](http://www.RSNhope.org)  
Phone: (818) 543-0896 Email: [info@RSNhope.org](mailto:info@RSNhope.org)



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This material was prepared by the IPRO ESRD Network Program, under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. The contents presented do not necessarily reflect CMS policy.  
CMS Contract Number: HHS-500-2016-00019C