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PAC Speaks A NEWSLETTER FOR PATIENT ADVISORY COMMITTEE REPRESENTATIVES



Better healthcare, realized.



About Me: Keith Taylor, PAC Chair North Carolina, SME, Medical Review Board Member

My name is Keith Taylor and I am an employee at a company called eTix in the client services department. I am happily married and have two cats, Elle, Prim and a dog, Coby Jack. I have been living with kidney disease since 2011. I had spent five years on hemodialysis, and in 2016, switched to Peritoneal Dialysis (PD). I serve as a patient Subject Matter Expert (SME) for the ESRD National Coordinating Center's (NCC) Patient and Family Engagement Learning and Action Network. I have been a board member of the NCC and a Patient Advisory Committee (PAC) Chair for Network 6 for two years

You Have Options! Peritoneal Dialysis

What is Peritoneal Dialysis (PD)

Peritoneal dialysis uses a special solution (called dialysate) that flows through a tube into your abdomen. After a few hours, the dialysate takes wastes from your blood and can be drained from your abdomen. After draining the used dialysate, your abdomen is filled with fresh dialysate, and the cleaning process begins again.

Hemodialysis to PD: My Transition

As told by Keith Taylor, North Carolina

There were many hoops to jump through with hemodialysis. While I would not consider my experience with in-center hemodialysis negative, it was very limiting. It's very difficult to find a job that accommodates regular dialysis treatments. I tried different dialysis shifts to work around my employer's schedule, but I found that dialysis made full time work-life balance impossible. Dialysis also makes travel difficult. For my business trips, I would have to call ahead and work with clinic staff to arrange treatments at a nearby clinic. Occasionally, these plans fell through putting my health at risk. When a dialysis treatment during a business trip fell through and left me without treatment for four days,

I decided to try a home-based treatment option.

My wife and I started looking at home treatment options. I knew that home hemodialysis would not be an option, because ironically, my wife cannot see blood without passing out! I thought I was out of options until my dietitian suggested PD. After further consideration, I asked my doctor, who connected me to my wonderful on-call nurse, Luanne. We set up a meeting with the surgeon who told me about the risks and benefits of PD and the surgery to put a catheter in my stomach. Luanne taught me how to perform PD for myself, and she and my doctor adjusted the treatment based on my needs.

Two weeks later, I felt confident in my ability to treat myself. I start setting up my PD Cycler around 9:45 p.m. I receive my treatment while I'm asleep. In the morning, after I wake up, I clean the cycler, and can go about my day. PD has allowed me to have more freedom to focus on my work and my family. Everyone can see a difference!



Patient Considering PD Should:

- Dedicate a space in your house for PD supplies. There are a lot of materials and they can get cluttered if you aren't careful.
- Take training seriously and read your manual! It seems intimidating at first, but the more time you spend practicing with your nurse, the easier it becomes. You can do it!
- Take your time cleaning your materials. Infection is common with PD. Your training will help you prevent infections.
- Make your schedule and stick with it! PD requires dedication, but the freedom and energy you gain is worth it.

Don't let the horror stories scare you- PD doesn't work for everyone, but it is still a life changing option for many people! Talk to your doctor before ruling out PD as a treatment

Resources

- National Kidney Foundation (NKF) Website: https://aakp.org/support-groups/ Call 855-653-7337 (855-NKF-PEER) or email nkfpeers@kidney.org
- Home Dialysis Central Website: www.homedialysis.org
 Phone: (608) 833-8033 E-mail: info@homedialysis.org
- National Institute of Diabetes, Digestive and Kidney Diseases Website: www.niddk.nih.gov Phone: 1 (800) 860-8747 E-mail: healthinfo@niddk.nih.gov



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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 Web: 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 Web: 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 Web: 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 Web: network9.esrd.ipro.org

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