

PARTNERS IN RESEARCH QUARTERLY



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<http://delaware-ckd.org>

IN THIS ISSUE

We Need YOU

How PCOR guides research to investigate what matters to patients. Page 1

Home Dialysis

Taking the mystery out of home dialysis. Page 2

Delaware Support Groups

Learn about public support groups in Delaware for dialysis patients, transplant patients, and their families. Page 2-3

Community Forum Recap

A series of four open forums united community and research understanding. Page 3

Save the Date!!!

Come to our second conference on September 15, 2017. Page 4

Why We Need YOU!

Holly Archinal

You may have heard the terms 'patient-centered research' and 'patient-centered outcomes' - but what do they really mean? Patient-centered means focused on the patient. In **healthcare**, this means that treatment is based on what the patient thinks is **most important**.

What does this have to do with **research**? Patient-Centered Outcomes Research (PCOR) is built on the idea that—in order for research to be effective—it is important to know what patients want scientists to investigate. Outcomes research compares treatments, procedures, and interventions based on their outcomes. PCOR uses **outcomes that matter** to patients, such as quality of life, fatigue, or pain.

PCOR is fast becoming very popular, and this is because in the past, research did not always investigate things that help patients directly.

To put the patient at the center of research for PCOR, we need to know **what patients care about** the most, because what is interesting to the researcher may be less important to the patient or

have less **impact** on patients' daily lives.

For instance, do patients worry more about a cure for CKD or management of the condition? By **engaging** patients, their families and caretakers, and care providers like doctors and nurses in the research process, we can **focus** our research on finding information that will help make **big decisions** and **daily choices** easier for patients with CKD.

PCOR sets out to help patients, physicians, caregivers and others make decisions about the healthcare options that work best for each individual. We are dedicated to ensuring our research will **improve the health and care** of everyone living with CKD. To do this—we **need you**.



Home Dialysis in Delaware

William Murray

When kidneys start to fail, several options are available to patients to receive dialysis: center hemodialysis and home dialysis, which includes peritoneal dialysis and hemodialysis.

Home hemodialysis (HHD) can be done at the patient's home with an adapted hemodialysis machine. A care partner is required as well as extensive training.

The patient and care partner are both trained on how to set up the machine, perform the HHD procedure, and troubleshoot any issues that may occur. One benefit of HHD is that it can be done on a

convenient schedule for the patient and his or her care partner.¹

According to the **United States Renal Disease System** 2016

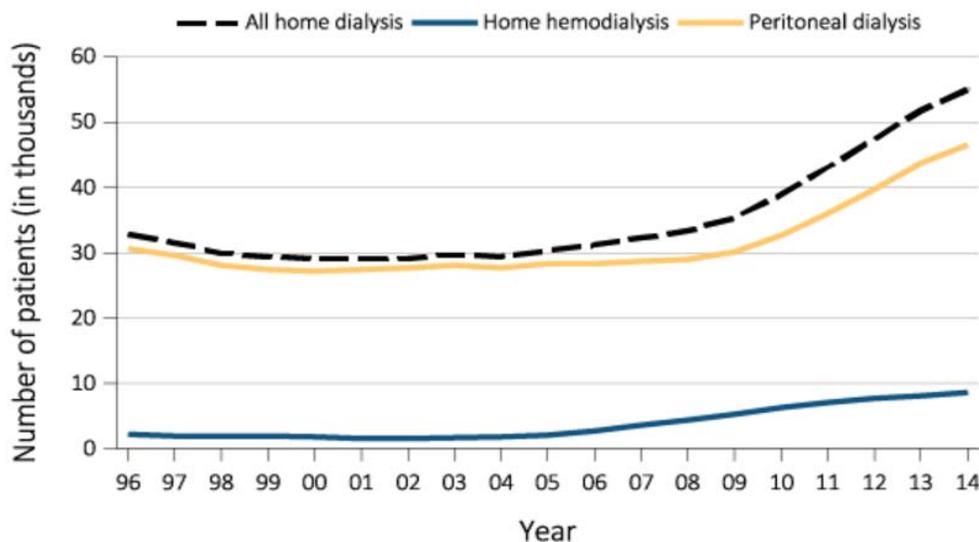
report,² the use of home dialysis (peritoneal dialysis or home hemodialysis) among patients with end-stage renal disease (ESRD) has increased appreciably in recent years. Among home dialysis patients, the proportion using hemodialysis was over 2.5-fold higher in 2014 (15.6%) than in 2000 (6.2%).



Example of a home hemodialysis machine.

References:

1. Dialysis Patient Citizens Education Center. <http://www.dpcedcenter.org>. Accessed May 9, 2017.
2. United States Renal Disease System. 2016 USRDS annual data report: Epidemiology of kidney disease in the United States. National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases; Bethesda, MD; 2016.



Thousands of patients using home dialysis in the United States, 1996-2014.

DIALYSIS SUPPORT GROUP

Dialysis patients interested in meeting with others can attend the **Home Dialyzers Support Group**. Group sessions consist of an **educational** portion followed by time for **questions and answers** to discuss issues with treatment, treatment options or just support.

The group is **open to anyone** in any stage of CKD and for any type of dialysis—peritoneal dialysis, home hemodialysis or in-center dialysis. Our goal is to take the fear and mystery out of performing dialysis at home so that more people can experience the freedom and results.

The support group is held **monthly** on the 4th Monday of each month from **5:30 to 7:00**, at the North Quarter Creole, **837 N. Union Street, Wilmington**.

For questions or to RSVP, contact Bill Murray at (302)275-4665 or shmrckpl@comcast.net.

Support group sponsored by NxStage.

TRANSPLANT SUPPORT GROUP

Patient support groups for **kidney transplant patients and their caregivers** are held quarterly at Christiana Hospital and facilitated by the Transplant Social Worker, Eileen Edge, LCSW.

There is **much to be learned** from talking to others who are “walking your walk” as an organ recipient. Patients find the meetings and hearing how others have managed their experiences to be both **supportive and educational**.

Educational topics presented cover a broad range including **food safety** for recipients, surviving the **holidays**, **medication management**, new **immunosuppressants** on the horizon, **returning to work** after transplant, coping with **stress**, and others.

Caregivers have an opportunity to get **peer support**, which is helpful to reduce stress arising from being in a new situation and dealing with unfamiliar health care responsibilities.

Meetings are generally scheduled for the 3rd Wednesday of the month on a **quarterly** basis. Upcoming 2017 meetings will be held on 9/20/17 and 11/15/17 at 6:00pm in **Conference Room #2115 in Christiana Care Medical Arts Pavilion 2 (MAP2)**.

For more information, call the Transplant Program Office at (302) 623-3866.

Community Forum Recap

Claudine Jurkovitz, MD, MPH

To **strengthen our partnership** and better **understand each other**, we organized a series of four town halls/open forums in early 2017.

The **January** meeting focused on Patient-Centered Outcomes Research (PCOR). **Coordination of care** between primary care physicians and specialists was selected as one of the most important topics for PCOR.

Patients pointed out that most of the time, they were in charge of keeping all their providers in the loop, and regretted that there was **little direct communication** between physicians. In many cases, faxing information from one practice to another is still used but is not a reliable method as paper can be lost and the information may not be entered into the electronic health record (EHR).

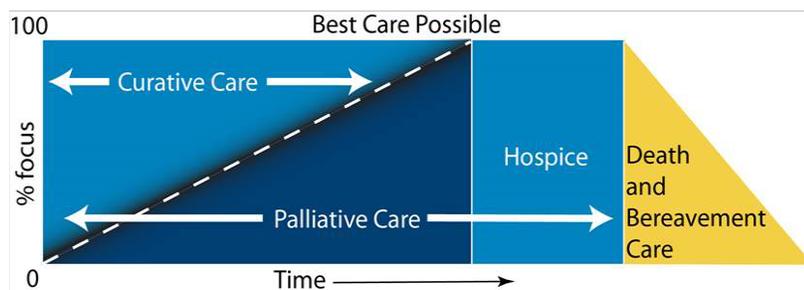
To improve communication between providers, everyone agreed that **improving EHR system connectivity** would be ideal, but other methods such as texting or emails could be used as long as the information was transmitted in a secure, confidential and reliable way. Many **opportunities**

for research were discussed!

The **March** meeting focused on epidemiology and **comparative effectiveness research**. Dr. William Weintraub, former John H. Ammon Chair and Cardiology Section Chief at Christiana Care and an internationally recognized clinician-scientist with extensive leadership in clinical trials and comparative effectiveness studies, led the discussion by first explaining how the science of **epidemiology** began and giving some examples of famous epidemiologic studies such as the Framingham Heart Study which led to the identification of the major risk factors for cardiovascular disease and the British Doctors Study in the 1950's that first showed the link between smoking and lung cancer. An animated discussion about comparative effectiveness science and how it could be applied to questions that matter to patients and other stakeholders followed.

Dr. John Goodill, Medical Director of the Palliative Care services at Christiana Care and Director of the

(Continued on page 4)



Comparison between palliative care and hospice care.

Partners in Research: Developing a Patient-Centered Research Agenda for Chronic Kidney Disease (CKD)

Chronic Kidney Disease (CKD) and end stage renal disease (ESRD) are serious and costly diseases. CKD affects more than 20 million adults, and is seen most often in individuals over 60 years of age. Diabetes and hypertension are the most frequent causes of CKD in the United States.

We invite you to **attend our second conference** which is part of a two-year project to **engage stakeholders** as we address the impact and burden of CKD and ESRD in Delaware. Patients and their supporters, providers, payers, researchers, and policy makers are all encouraged to attend this event.

DATE: Friday, September 15th

TIME: 8:00 am to 1:00 pm (Registration opens at 7:30 am)

LOCATION: John H. Ammon Medical Education Center at Christiana Hospital



Please join us as we **work together to** address CKD and ESRD.
Together, we will **make a difference.**

(Continued from page 3)

Supportive and Palliative Care Education and Outreach was our guest speaker in **April** and led a thoughtful discussion on **palliative care** in the context of end-stage renal disease.

He defined palliative care and explained the **difference between palliative care and hospice**. He emphasized that palliative care was appropriate at any age and at any stage in a serious illness and could be provided along with curative treatment. He highlighted the importance of **Advanced Care Planning** and of documenting **Advanced Directives** and described the Delaware Medical Orders for Scope of Treatment

program, which is designed to improve the quality of care people receive at the end of life by **translating patient goals and preferences into medical orders** (<http://delawaremost.org/>).

We concluded our town hall/open forum series in **May** with a wonderful presentation from Anahi Santiago, the Chief Information Security Officer at Christiana Care, about **confidentiality and safety of data**. We learned that healthcare was the most attacked industry worldwide and in the US. She also emphasized that hackers target people not technology, and that they trick us into revealing passwords and personal identifiers. As one of the participant stated: "This was an **eye-opening** discussion"!

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