

PARTNERS IN RESEARCH Quarterly February 2017

<http://delaware-ckd.org>

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Raising Awareness for Kidney Disease

Sarahfaye Dolman, MPH, MTA

SAVE THE DATE

World Kidney Day Event

March 9, 2017, 12:00-3:00pm
Henrietta Johnson Medical Center,
601 New Castle Ave,
Wilmington, DE 19801
(302)655-6187

Since 2006, organizations around the world have been spreading the word about kidney disease every year on March 9 to **raise awareness** of this global disease, and this year the Partners in Research team is joining the effort.

This year's theme is the **impact of obesity** on kidney disease. In partnership with Henrietta Johnson Medical Center (HJMC), we will be

offering **free health screening** at HJMC for diabetes, blood pressure, and BMI – all risk factors that can lead to the development of chronic kidney disease or speed progression of the disease.

Screenings will take place from 12-1:30pm at HJMC. During this time, **free lunch** will also be available.

Following the screenings, there will be a **panel discussion** featuring care providers and patients who can answer your questions and share their experiences with kidney disease.

For **questions or directions**, please call 302-655-6187.

For more information about **World Kidney Day**, visit their website at www.worldkidneyday.org.

World Kidney Day

HJMC and Partners in Research are hosting free health screenings and a panel discussion for World Kidney Day.

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Dialysis Patient Citizens is fighting to protect health coverage for dialysis patients—and winning.

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One patient's perspective on living with PKD.

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Your research questions fell into 19 themes. What does that tell us?

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Home Hemodialysis

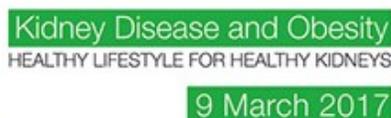
The benefits of home hemodialysis as told by a patient.

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Speak Up at our Town Halls

We want to know what you think about these important topics relevant to research related to CKD. Here's your chance to speak up.

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Protecting Health Coverage for Dialysis Patients

Hrant Jamgochian, J.D., LL.M.

For people with end-stage renal disease (ESRD), **health insurance is essential** to receiving dialysis and other critical care. Thanks to federal law, ESRD patients can enroll in Medicare at any age. But if they would rather keep their doctors and specialists under a private insurance plan, they can receive **help paying their insurance premiums** from charities such as the American Kidney Fund.

Unfortunately, insurance companies want to **take charitable financial assistance** away from dialysis patients, and they have convinced the federal government to **impose severe restrictions** that would achieve this goal. Dialysis Patient Citizens and other

patient advocates sued the government in January to keep it from ripping financial support away from dialysis patients, which we argued could force them to drop their insurance coverage. A federal judge agreed with us and issued an injunction preventing **this onerous policy** from going into effect.

Insurance companies claim that Medicare is adequate for ESRD patients. But **private insurance** plans can offer patients better benefits, including care coordination services, than Medicare. And private plans limit what patients must pay out of pocket for their care – Medicare doesn't. Insurers aren't concerned about the



costs imposed on patients. Their goal is to shift responsibility for chronically ill patients to Medicare.

We are **grateful** that the court recognized the right of ESRD patients to choose their health care plan, and we hope the Trump administration will support this right as well.

Dialysis Patient Citizens (DPC) is America's largest patient-led organization representing dialysis patients. DPC's membership consists of more than 28,000 dialysis and pre-dialysis patients and their families.

In Your Own Words: Living Life to the Fullest with Polycystic Kidney Disease

Shay Scott

Anyone who knows **Lawondale Parker** would describe her as optimistic, caring, or a busy community volunteer. You would not hear **Polycystic Kidney Disease** or **Kidney Transplant** would be the last things you would expect to hear, but these phrases also describe her. Lawondale has been battling Polycystic Kidney Disease (PKD) for over 40 years, which led to a Kidney Transplant in 2012. Lawondale lost her mother to CKD when she was a young child, and that shaped her resolve to **live life to the fullest**.

Knowing that life comes with the gift of choice, Lawondale decided to stay positive and control the things she could. Keeping to a balanced diet and exercising help her **control her health**. Even with Lawondale's love of sweets, she makes the decision to limit her daily sugar intake, which contributes to maintaining a **balanced diet**. Lawondale dances, walks, and goes up and down her stairs to get in her **daily exercise** — all activities she does at home. Each time she makes a **healthy**

choice, Lawondale manages her health instead of a disease.

As a retired registered nurse, Lawondale knows the importance of **being an active participant** in her health, and as a patient she understands how hard it is to make **lifestyle changes**; hard but not impossible. Lawondale also knows her commitment to **making healthy choices** will not cure her Polycystic Kidney Disease, but it lets her live her life **on her own terms** and improves her **quality of life**. She credits her ability to thrive with PKD to **participating in her care**, keeping a **positive attitude**, and **being honest** with herself and with her doctors.

"Making lifestyle changes is hard — not impossible."

You Asked: Themes of Questions from Partners in Research Conference

Claudine Jurkovitz, MD, MPH

Chronic Kidney Disease (CKD) is **highly prevalent** in the United States and leads to numerous comorbidities. By merging electronic health records we have created a **registry of patients** with CKD in **Delaware**.

To make this registry **useful and helpful** to patients as well as health care providers, we asked everyone at the Partners in Research 2016 conference to identify questions that are most **important to the community** of patients with CKD and to those who care for them.

We collected a total of **122** questions and identified **19** themes across the questions (shown at right).

Common concerns included **educating** patients, physicians, and the community about CKD; **improving communication** between patients and providers; and improving communication and **coordination of care** between providers.

Coordination of care between primary care doctors and specialists was further discussed at our **first Town Hall** meeting on January 24th (see page 4).

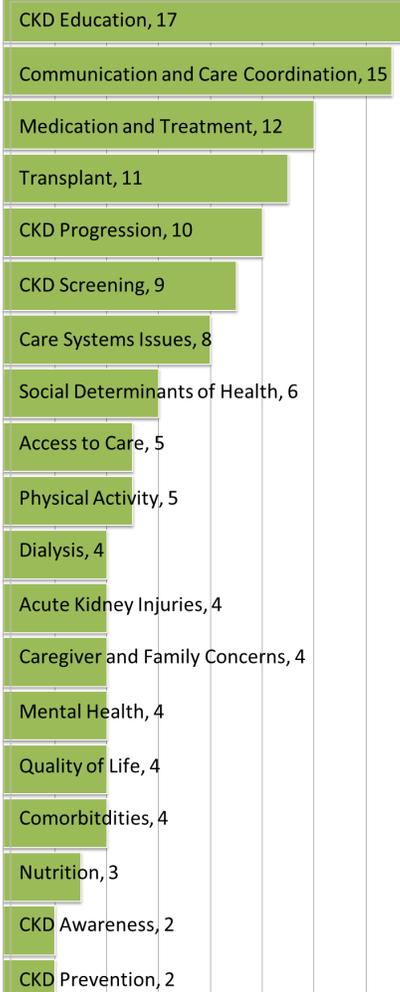
Patients pointed out that most of the time, they were in charge of **keeping all their doctors in the loop**, and regretted that there was **no direct**

communication between doctors. In many cases, faxing information from one doctor's office to another is still used but paper can be lost and the information may not be entered into the electronic health records.

Everyone at the Town Hall agreed that **improving electronic health records** system connectivity would improve this problem, but other methods such as **texting or emailing** between doctors could be used as long as the information was sent in a secure, confidential, and reliable way.

More to follow at our Town Hall meeting on **May 24**, where we will discuss security of data! See page 4 for more information about the Town Hall meetings.

CONFERENCE THEMES



Workgroups identified research questions at the Partners in Research 2016 conference.

FOR MORE INFORMATION

Learn more at our website:

<http://delaware-ckd.org>

In Your Own Words: Benefits of Home Hemodialysis

William K. "Bill" Murray

Bill was a self-employed plumber for his company, Shamrock Plumbing, until Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD) forced him to shutter it and **take disability**.

He was biopsy diagnosed with IgA Nephropathy in 1996, and the nephrologist told him that he would **require dialysis to live**. He followed the doctor's orders including lifestyle changes, diet restrictions, and a mind boggling amount of medicine that was constantly changing. Despite his best efforts, his kidney function dropped into the danger zone after 17 years and he went into **end stage renal failure**.

Research into his treatment options revealed that **home dialysis** was the **most effective** and had the **best results**, and he made the switch to home hemodialysis (HHD) after 10 months on peritoneal dialysis. He has continued this mode of treatment very successfully since.

Bill is constantly promoting the advantages of **home hemodialysis**: the **flexibility** of days performed, less or no **physical draining**, and a dialysis process more similar to natural kidney function.

Bill's experience has **ignited his passion** for early detection, education,



organ availability and donor support. He has become an active fundraiser in local Walks, and an active advocate locally and nationally. He serves as a peer mentor and is also a patient representative and subject matter representative. Bill has been honored nationally for his advocacy work.

SAVE THE DATE

Partners in Research Town Halls
Christiana Hospital

John H. Ammon Medical Center

<http://bluejeans.com/101777621>

When:

March 21, 2017 at 5:00pm

April 19, 2017 at 5:00pm

May 24, 2017 at 5:00pm

Contact:

[Sarahfaye Dolman](mailto:Sarahfaye.Dolman@ChristianaCare.org), (302)733-5868

Our first Town Hall was held in January and while we did not have many members of the CKD community in attendance, we had representation from both patients and care providers

Town Halls: Partner with Us

and a **healthy discussion** involving patient-centered outcomes research.

We are eagerly looking forward to our next Town Hall sessions and **hope you can join us**. If you cannot make it in person to Christiana Hospital, you can join us online at <http://bluejeans.com/101777621>.

The March 21 Town Hall will focus on **registry data** and how it can be used for research. The April 19 Town Hall will involve **End Stage Renal Disease and end of life care**. The May 24 Town Hall will be about **confidentiality and safety of data** (see page 3).

Several of these topics will be discussed in the context of the

research questions raised at the Partners in Research 2016 Conference. We look forward to taking a more in depth look at these topics and **starting a dialogue** in the CKD community.

Drinks and snacks will be available at all Town Hall meetings.

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Contact:

Sarahfaye Dolman
(302)733-5868 or (302)530-1873

Sarahfaye.F.Dolman@ChristianaCare.org

<http://delaware-ckd.org>