



<http://delaware-ckd.org>

Conference Recap

Our **Partners in Research 2016** conference was a success, with almost **200 participants** in the morning sessions. Our line-up of speakers received high praise.

The morning started with a review of the state of Chronic Kidney Disease (CKD) in the US and in Delaware. Dr. Shahinian from the University of Michigan set the stage by describing all the sources of data related to CKD available in the US, and Dr. Swanson, Director of Kidney Transplantation at Christiana Care, showed us **sobering data** about the number of people with CKD in Delaware.

Dr. Crews from Johns Hopkins demonstrated that access to care and **access to healthy food** are major factors explaining why some people with CKD progress faster than others.

Nancy Scott, Bill Murray, and Tracy Zigman received a standing ovation for narrating their own experiences

with kidney disease. Tracy moved the audience to tears when she unfolded the long list of **potential side effects** to the medications that her little girl, Izzy, takes for her nephrotic syndrome.

Electronic health records, the data systems that are used by doctors and hospitals, do not talk to each other, and there is no consensus on which information to transfer from one health care provider to another for patients who have CKD. This is a problem because these patients often have other health conditions and have to see many doctors and specialists.

To address this problem, Jenna Norton from the National Institute of Health described an initiative to standardize the information that needs to be transferred from one health care provider to another to **improve the coordination of care**.

(Continued on page 2)

PARTNERS IN RESEARCH Quarterly November 2016

IN THIS ISSUE



Conference Summary

Hear all about the Partners in Research 2016 conference and Save the Date for next year.

Pages 1-2



Your Research Questions

The chronic kidney disease community's burning questions revealed.

Page 3

Recap Continued...

(Continued from page 1)

The morning sessions were followed by a working lunch with 3 uplifting presentations. Dr. Salam first described what is being done at Christiana Care to improve the health outcomes of complex patients. Linking data and good case management are key! Dr. Schwartz explained why patient-centered outcomes matter and Dr. Jenkins highlighted the importance of **community engagement** for meaningful research.

No rest for the weary! The lunch sessions were followed by very productive afternoon workgroups. Turn to page 3 for a workgroup summary.



Finally, please visit our website at <http://delaware-ckd.org>. The conference was recorded and each presentation will soon be available on the website as well as information about the next workshops and next year's conference.

SAVE THE DATE

Partners in Research 2017 Conference
September 15, 2017
Christiana Hospital, John H. Ammon
Medical Education Center
Newark, DE 19718



There's **so much exciting work** being done that we couldn't fit it all in one day for the conference, so we're holding monthly Community Town Halls starting in January 2017 to build on some important topics related to patient-centered research surrounding the care, treatment, and management of CKD.

Monthly Community Town Halls

We want you to join us for these participatory sessions. Come to Christiana Hospital (light snacks provided) or join us **online** using your computer, tablet, or phone at <https://bluejeans.com/101777621>.

The first session will be held on January 26, 2017 and will explore **patient-centered outcomes research (PCOR)**. What is PCOR? What does it look like? How can you get involved? And why is it so important to CKD in Delaware?

Future sessions will focus on

registries, confidentiality and safety of data, and end of life treatment for End Stage Renal Disease.

SAVE THE DATE

January Community Town Hall
January 26, 2017
Christiana Hospital, John H. Ammon
Medical Education Center Room 2E56
Newark, DE 19718

<https://bluejeans.com/101777621>

Register online:

<http://whoozin.com/JT6-TFA-TJ6Y>

or call (302)733-5868



Your Research Questions Revealed

Between 80 and 90 people participated in the afternoon workgroup sessions. Participants were asked to identify kidney disease-related research questions and outcomes that were the **most important** to them.

There were 4 workgroups focusing on CKD in general, one workgroup specifically for dialysis, and one workgroup specifically for transplantation. Each workgroup had a moderator and scribe.

Workgroup participants kept track of questions throughout the morning sessions to bring to the workgroups. Questions were written on a flip chart and then the

fun began—workgroup participants went through a ranking exercise! Discussions were lively and many questions were raised! All the questions were later entered into a database.

When we examined the highest ranked top ten questions, **coordination of care** was a top priority for both patients and providers. One workgroup participant asked, “Who among the providers is in charge—the primary physician, the nephrologist, the transplant team?” Another asked about how we can facilitate **sharing patients information** between providers.

Other topics highly ranked by patients included questions

FAST FACTS

122

122 research questions were asked by conference participants, with 109 raised during the workgroups.

16%

Care coordination was related to 16% of questions, including EHR issues.

11%

Education of patients, families, or communities was involved in 11% of questions.

about the effectiveness of **early screening** and screening of children to decrease disease progression, improving accessibility and coverage of **transplant medications**, genetic factors to identify nephrotic syndrome and

(Continued on page 4)

FOR MORE INFORMATION

Learn more at our website:

<http://delaware-ckd.org>



Research Questions Continued...

(Continued from page 3)

glomerular disease, and incentives to **improve physician communication** with patients.

In addition to coordination of care, the questions ranked highest by providers were related to the most effective way to **prevent CKD** and appropriate use of Angiotensin Converting Enzyme Inhibitors or Angiotensin Receptor Blockers. Other questions raised by providers

related to **mental health support** for CKD patients at diagnosis and during treatment and should the prevention of CKD progression and treatment of complications be different in patients with HIV.

Except for screening and prevention, the 10 highest ranked questions by researchers differed from those ranked by patients and providers. Researchers asked about methods for **families to provide**

support for people with kidney disease and about

interventions that include the entire family, not just the patient. Researchers also raised questions about the role of **obesity and physical activity** in kidney disease and would like an indicator for physical activity to be included in the Delaware CKD registry. Last, researchers asked, "What is the clinical impact of lack of access to medications and what is the most effective way to **expand organ donation?**"

Analysis of all the questions is ongoing and we'll continue to share our results on the website.



Evaluations were handed out for the morning sessions and for the afternoon workgroups to get feedback about the conference. The evaluations included general questions about the conference, questions about the speakers, and questions about the workgroup sessions. We collected 59

and we are very pleased that 91% of people agreed that the **topics were interesting**. Furthermore, 85% of people felt the **number of speakers was appropriate** but 52% of people would have liked **more time to ask questions** to the speakers. Finally, 74% of people thought that the topics

Conference Evaluations

evaluations.

Overall, 90% of people agreed that the conference was **well organized**,

addressed their concerns.

Additionally, everyone loved the **kidney-friendly food** choices and felt the conference was **useful** (90% agreement).

**PARTNERS IN
RESEARCH Quarterly**

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