



LEFT: Dr. Bessie Young, nephrologist at the Kidney Research Institute, and Dr. Wylie Burke, genetics ethicist at the University of Washington, led a meeting in March for stakeholders about APOL1 testing.

RIGHT: Meeting attendees listen to a panel discussion about APOL1 genetic testing. Turn to page three to read more about this project.

## A continued focus on engaging patients in research

A message from the director

**DR. JONATHAN HIMMELFARB**

2018 has brought exciting new developments to the Kidney Research Institute. In February, we welcomed Glenda V. Roberts as our director of external relations and community engagement. Glenda comes to the KRI with a strong background in kidney disease advocacy work, coupled with years of experience as a senior business executive. Glenda will focus on increasing community awareness of the KRI and kidney disease as well as foster resources for patients and research.

Early this year Dr. Ian de Boer, associate director at the KRI, was elected to the America Society for Clinical Investigation. Membership to ASCI is nomination based and reserved for investigators who have had significant accomplishments early in their career. Ian's election to this prestigious society reflects his dedication to nephrology research early on in his career.

Research from our investigators continues to generate interest in the academic community. In February, Dr. Nisha Bansal's research on cardiovascular disease in chronic kidney disease patients was published in JAMA Internal Medicine. Her surprising findings have important clinical implications in treating kidney disease patients with heart disease. The American Journal of Kidney Diseases recently published Dr. Ann O'Hare's strategies for patient-centered care in renal medicine. Ann highlights challenges faced in caring for patients with kidney disease and suggests solutions to providing better care. Also in this newsletter, you'll read about a recent meeting, led by investigator Dr. Bessie Young, that brought stakeholders together to hear about recent efforts to understand community perspectives on the appropriate use of APOL1 testing.

We are looking forward to Northwest Kidney Centers' Breakfast of Hope May 10 in Seattle, a wonderful annual event that raises money for essential patient services.

Thank you for your continued support of the Kidney Research Institute.

## ON THE HORIZON

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**TRANSFORMING LIVES THROUGH  
INNOVATION AND DISCOVERY**

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# Kidney Research Institute investigator Dr. Ann O’Hare publishes strategies for patient-centered care in renal medicine

In February, the American Journal of Kidney Diseases (AJKD) published an article by Kidney Research Institute investigator Dr.



Dr. Ann O’Hare.

Ann O’Hare discussing five strategies to meet the challenge of patient-centered care in renal medicine.

Patient-centered care is clinical care that takes into account patient values and preferences. Health care delivery has historically been organized by diseases and organ systems rather than around patient needs. While the notion of patient-centered care is generally well accepted, implementing it calls for a frameshift in how care is delivered.

In her article, Ann outlines five overlapping strategies that have been useful in centering care on her renal patients. The strategies include listening to patients, making time for patients, being willing

to go beyond her job description, reimagining what it means to provide “good” care, and seeing the value of relationship building.

Ann recognizes the challenges in delivering patient-centered care.

“Because the health systems in which we work, the medical schools, residency and fellowship programs in which we trained, and the research programs we are part of are far from patient-centered, I have found that I have had to consciously set aside much of what I learned in training in order to care for my patients as people.”

She further concludes that while applying strategies for patient-centered medicine will initially be difficult in a complex health care environment, it will ultimately improve the experience of both patients and providers.

Find the full article at [www.ajkd.org](http://www.ajkd.org).

“The notion of ‘centering’ care on our patients is in fact quite revolutionary.”  
- Dr. Ann O’Hare

# Kidney Research Institute associate director Dr. Ian de Boer elected into the American Society for Clinical Investigation

Dr. Ian de Boer, associate director at the KRI and professor of medicine at University of Washington, was recently elected into the American Society for Clinical Investigation, a renowned honor society for physician-scientists.



Dr. Ian de Boer.

Established in 1908, the ASCI is one of the oldest and most respected medical honor societies in the U.S. The society includes more than 2,800 physician-scientists from all medical specialties and is focused on supporting research into basic mechanisms and/or treatment of human disease.

Ian was one of 78 medical researchers whose nomination was accepted in 2018. This distinction is conferred only on investigators who have made significant scientific advances prior to the age of 50.

Membership in the ASCI is attained exclusively by nomination from a current member, and only after intense review. Ian was

nominated by Dr. Stuart Shankland, head of the Division of Nephrology at University of Washington. The KRI now has three ASCI members on its staff: Drs. Ian de Boer, Bryan Kestenbaum and Stuart Shankland.

Induction into the ASCI allows Ian to work with scientists beyond the scope of nephrology, opening up the possibility of new discoveries from shared knowledge.

“At the KRI, we are very collaborative and broad thinking,” explains Ian. “Collaboration with researchers from other complimentary disciplines is important so we can bring the best science to bear to improve care for patients with kidney disease.”

Ian began his patient-oriented research as a nephrology faculty member in 2006 and has been with the KRI since it was founded in 2008. Since the beginning, he’s focused his research on diabetic kidney disease, with a related interest in vitamin D. He’s following up and extending early findings, with the goal of translating discoveries into improvements in clinical care.

Asked why he chose nephrology, Ian says, “I like the patients as well as the complexity and critical thinking required to study kidney disease. I also appreciate the variety of activities and settings of nephrology in general, and academic nephrology in particular.”

# Investigator Dr. Bessie Young leads meeting to gain insight about APOL1 genetic testing from key stakeholders

In 2016, Dr. Bessie Young, investigator at the Kidney Research Institute, and Dr. Wylie Burke, professor and former chair of the Department of Bioethics and Humanities at the University of Washington, secured funding for a research grant related to a new genetic finding — the Apolipoprotein 1 variant or APOL1 for short.

**About the APOL1 project**  
This project builds upon a 2010 breakthrough where two genetic variants in the APOL1 gene were found to be associated with a family of common kidney diseases in 13 percent of people with sub-Saharan ancestry. The finding may provide an explanation for the higher rates of kidney disease in these populations.

This project undertaken by Bessie and Wylie seeks to understand community perspectives about the responsible use of APOL1 testing in research, clinical care and kidney transplant programs, and allows impacted populations to provide input from a patient perspective. As part of the project, Drs. Erika Blacksher and Ebele Umeukeje have led three community deliberation sessions — in Jackson, Miss., Nashville, Tenn. and Seattle, Wash. — that enabled the impacted community to weigh in on testing efficacy and protocols, and whether or not participants should be allowed to receive test results.

**Stakeholder meeting held to discuss findings**  
An APOL1 stakeholders meeting, featuring expert presentations, a community-deliberants panel discussion and multiple breakout sessions, was held in Bethesda, Md. in late March. Stakeholders reviewed the latest research findings, assessed the implications for impacted communities and developed recommendations for action plans for both clinicians and patients. Participants identified

areas of consensus and disagreement between community representatives and researchers and recommended actions to educate clinicians and the community. The results of the research will be published later this year.

Meeting attendees from the University of Washington included the following: Dr. Jonathan Himmelfarb, director of the KRI and professor of medicine; Dr. Bessie Young, KRI investigator and professor of medicine; Dr. Wylie Burke, professor and former chair of the Department of Bioethics and Humanities; Dr. Erika Blacksher, associate professor and director of undergraduate studies in the Department of Bioethics and Humanities; Dr. Malia Fullerton, associate professor in the Department of Bioethics and Humanities, and Glenda V. Roberts, director of external relations and patient engagement at the KRI. Other participants included representatives from the three community deliberative groups, community advisory boards based in Jackson, Nashville and Seattle, NIH/NIDDK, American Research Institute, NIH/NIDDK, American Association of Kidney Patients, American Society of Nephrology, American College of Medical Genetics and Genomics, American College of Physicians, National Kidney Foundation, researchers and ethicists.



Latoya Lofton and Cynthia Montgomery took part in one of the APOL1 project’s community panels.

# Study by investigator Dr. Nisha Bansal shows people with chronic kidney disease who also have heart failure may not benefit from implantable cardioverter defibrillators

In February, results of Kidney Research Institute investigator Dr. Nisha Bansal’s study on implantable cardioverter defibrillators (ICDs) and chronic kidney disease was published in the Journal of the American Medical Association, Internal Medicine.



Dr. Nisha Bansal.

The observational study looked at almost 6,000 patients with chronic kidney disease and heart failure. Study results showed that in chronic kidney disease patients, ICDs were associated with increased risk of hospitalizations.

“The finding surprised us,” Nisha said in an interview to the JAMA Network. “Chronic kidney disease is common in adults with heart failure, and is associated with a greater risk of heart attack. However, in this observational study we did not find a significant overall benefit from ICDs for patients with kidney disease.”

Study results and its clinical implications sparked intrigue in the medical community, with articles about this running in Medscape, MedPage Today, Healio and HealthDay.

This study was a joint collaboration between the University of Washington and researchers at Kaiser Permanente.



RETURN SERVICE REQUESTED

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## Longtime patient advocate Glenda V. Roberts joins the Kidney Research Institute as one of its directors

As director of external relations and patient engagement at the Kidney Research Institute, Glenda V. Roberts will work to increase awareness of the KRI amongst key constituents and help us further incorporate the patient voice into our research.

"I am honored that I'll have the opportunity to expose people to the potential of the life-enhancing research that the KRI is undertaking," says Glenda, "and to encourage kidney disease patients and the general public to support this work."

Diagnosed with kidney disease right out of college, Glenda knows the challenges patients face. She managed the progression of her disease through diet and exercise for decades while simultaneously rising through the corporate world, evolving from a software developer to a senior business executive. She was on hemodialysis at Northwest Kidney Centers as well as peritoneal dialysis at

home before receiving a transplant in 2010.

Together with her husband, Glenda co-founded OUIWorks.org, a nonprofit focused on providing support for kidney patients. She served most recently as CEO of Transplant House, a home away from home for people that come to Seattle to await or recover from a transplant. She was the patient-keynote speaker at Northwest Kidney Centers' 50th annual Breakfast of Hope and the emcee for the first annual University of Washington Medical Center Team Transplant Fundraising dinner. Glenda is also a member of the Patient Advisory Council at the KRI.

Glenda is a tireless advocate for patients at the local, state and national levels. Her personal experience with kidney disease combined with her knowledge of trends, treatments and current research will be invaluable toward increasing patient and community engagement.

'I am honored that I'll have the opportunity to expose people to the potential of the life-enhancing research that the KRI is undertaking'