



Matthew Risher at the 2019 Patient Advisory Committee meeting

Putting patients first

A message from the director

DR. JONATHAN HIMMELFARB

We hope that you and your loved ones are staying safe and healthy this year. The Kidney Research Institute continues to adapt and expand the scope of our research studies to fit emerging needs, while keeping kidney patients at the forefront of all our work.

KRI investigators continue to acquire new funding and launch studies in support of kidney patients. Inside, you will read about Dr. Nisha Bansal's new study KIND-HF, which will study kidney function in heart failure patients. Several investigators were recently funded to study COVID-19, a disease that affects kidney disease patients. Many of these funded studies have started or will start soon.

Patient engagement continues to be critical to the mission of the KRI. KRI Patient Advisory Committee member Marla Levy provides insight into her background as a patient advocate and the benefits patient advocacy has provided to her personally. She also offers guidance on how the KRI can continue to support kidney patients. In this newsletter, you will also learn about the recently completed PERL Study, including results of the study and its impact on diabetic kidney patient care.

The KRI continues to keep research participant and study staff safety as our highest priority, and we are continuing in-person research only when safe to do so. We will continue to adapt to changing circumstances and are, as always, appreciative of your support.

**TRANSFORMING LIVES THROUGH
INNOVATION AND DISCOVERY**

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KRI completes landmark “Preventing Early Renal Loss in Diabetes” (PERL) study

The KRI recently completed the “Preventing Early Renal Loss in Diabetes” (PERL) Study. PERL is a national clinical trial for people with type 1 diabetes who have early signs of kidney problems, with 16 recruitment centers in the US, Canada and Denmark. The goal of the study was to test a new way to slow loss of kidney function using a safe and inexpensive medicine. The PERL study was a double-blind study, where participants were randomly assigned to the study drug, allopurinol, or a placebo drug, and were unaware of their study assignment. The Kidney Research Institute, led by KRI investigators Drs. Ian de Boer, Irl Hirsch and Maryam Afkarian, served as one recruitment site for the study. Recruitment for the study took place at the University of Washington and 25 participants were enrolled between 2015-2017. Nationally, 530 participants were enrolled in the study. The last study visits took place throughout 2019, and 96% of enrolled participants at the University of Washington completed the study. Lead research coordinator Dawn Lum noted, “I feel fortunate to have been chosen to work on the PERL Study. When I began working with this cohort in 2015, I had no idea that these participants would become dear friends to me. We’ve celebrated weddings, grandkids and retirement!”

Participant engagement and retention were critical to the success of the study. As part of study, enrollment participants were followed up on for three and half years, and met with the research team for between 15-17 visits. Interested and eligible participants were also asked to enroll in optional PERL sub-studies to wear a continuous glucose monitoring (CGM) device or to have a biopsy done on their kidney.

A UW PERL participant who chose to also have a kidney biopsy described his overall experience. “My feeling about the PERL Study & research as a whole is positive. The potential benefits of research are so much greater than the inconvenience of participating. Staff scheduled appointments to coincide with doctor appointments to make it more convenient for me. All procedures that I underwent were explained to me by study staff & doctors in layperson language, so I understood what would be happening and felt comfortable participating. When I had the biopsy, it was slightly painful—was not as painful as I expected--but the pain went away quickly. The information that I got back was good news—my kidneys were not as bad as I thought they were! Every time I have had a chance to be part of research, I have done so, because it’s so important to finding answers for me & the Type 1 Diabetics that come after me.”

Results of the study were published in the New England Journal of Medicine in June 2020. In the article “Serum Urate Lowering with Allopurinol and Kidney Function in Type 1 Diabetes”, study investigators noted they had found no evidence of clinically meaningful benefits of serum urate reduction with allopurinol on kidney outcomes among patients with type 1 diabetes and early-to-moderate diabetic kidney disease. All PERL participants were notified of study findings at the beginning of this year.



KRI investigator Dr. Ian de Boer



Lead research coordinator Dawn Lum

When asked about the importance of the PERL study and its impact on patient care, Dr. de Boer noted, “The PERL study was a true landmark clinical trial. For many years, people have speculated about the role of uric acid in the development of kidney disease. PERL provides the strongest evaluation of this hypothesis to date. The answer was no, lowering uric acid does not help slow kidney disease progression. But it wasn’t just “no,” it was a clear, emphatic “no” because the study was so well done and the results were so precise. This is a testament to the dedication of the PERL participants and all of the staff that worked so hard to complete the study. The PERL trial helps guide the whole research enterprise to look toward other approaches to prevent kidney disease, and happily, more and more are being developed.”

The PERL study is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the Juvenile Diabetes Research Fund (JDRF)

PATIENT ADVISORY COMMITTEE (PAC) SPOTLIGHT

Interview with Marla Levy

Marla Levy, a member of the Kidney Research Institute's Patient Advisory Committee (PAC) since 2019, believes her life's purpose is to advocate for kidney patients. Several years ago, Ms. Levy underwent two heart surgeries over the course of ten days and suffered complications that included damage to her kidneys. Ms. Levy ultimately recovered from her complications but recalls the time immediately after her heart surgeries as one of confusion. For several years after this experience, Ms. Levy wished to have a community to share her experience with. That opportunity came in 2018, when she was invited to the National Institutes of Health (NIH) to share her story of survival with clinicians and scientists. This opportunity connected her with researchers around the country, including investigators at the Kidney Research Institute, and began her career as a patient advocate.



PAC member Marla Levy speaks at the 2019 IDEA's Conference

When asked if her participation in the PAC and as a patient advisor has benefited her own knowledge of her kidney health, Ms. Levy noted she has been introduced her to clinicians and scientists at the top of their field. Ms. Levy notes that she now understands the difference between acute kidney injury (AKI) and chronic kidney disease (CKD) and can explain what lab values mean. The opportunity to be a PAC member has given her a different perspective of her own health story.

When asked how the KRI can support kidney patients in the next ten years, Ms. Levy suggested the KRI keep doing what it does best – educate and empower patients through a broad scope of research initiatives. She noted that patient involvement in research could help them better understand their own disease. This type of engagement would also empower patients to feel like they are part of the research process. Ms. Levy encouraged the KRI to publicize our research and study results broadly, as the work being done would help not just patients, but their care partners, friends, community and their clinical care teams.

We thank Ms. Levy and all our PAC members for their time and commitment to the KRI.

Kidney Injury and Heart Failure (KIND-HF)



Dr. Nisha Bansal

Dr. Nisha Bansal has launched a new research study “Kidney Injury and Heart Failure (KIND-HF)”. This important research follows patients who are admitted to the hospital with a diagnosis of heart failure. Kidney function is a key determinant of management and prognosis in patients with heart failure, but current clinical measures of kidney function are inadequate for use in these patients. Nisha and the study team hope to study and compare traditional and novel measures of kidney function and the response to treatment for acute decompensated heart failure. This study builds on earlier work conducted by Dr. Bansal and KRI coordinators. The study team plans to enroll 400 patients and follow them for one year after they leave the hospital. “We hope the study will provide insights on how best to measure and monitor kidney function in patients with heart failure to improve their overall prognosis.” The study is funded by the National Institute of Diabetes, Digestive and Kidney Diseases (NIDDK).

📰 Also in the news

- Dr. Nisha Bansal is the 2020 recipient of the **American Society of Nephrology Distinguished Researcher Award**.
- Senior research fellow Dr. Simon Hsu won 2nd place in the clinical research category at the National Kidney Foundation's 15th Annual National Young Investigators Forum. His project is **“Serum 25-Hydroxyvitamin D Clearance Is Reduced in Chronic Kidney Disease”**
- Dr. Susan Wong is a recipient of the Doris Duke Charitable Foundation Clinical Scientist Development Award for her project **“Promoting Goal Concordant Care among Patients with Advanced Kidney Disease”**.
- Glenda V. Roberts published on a patient experience during COVID-19 **“The Early Days: The Postkidney Transplant Recipients' COVID-19 Journey”** in CJASN.
- Drs. Jonathan Himmelfarb and Rajnish Mehrotra review on the **“The current and future landscape of dialysis”** was published in Nature Reviews Nephrology.
- Drs. Bryan Kestenbaum, Ian de Boer and Leila Zelnick published results of the SUGAR study **“Tubular Secretory Clearance is Associated with Whole-Body Insulin Clearance”** in the Journal of Clinical Endocrinology & Metabolism
- Glenda V. Roberts, provided a patient viewpoint on her experience with the Kidney Precision Medicine Project in the article **“Precision medicine in kidney disease: the patient's view”** in Nature Reviews Nephrology.

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COVID Research at the KRI

As new data emerges showing COVID-19's serious impact on kidney disease patients, KRI investigators are expanding their current research to study the novel disease. Several investigators have received supplemental emergency funding to help understand COVID-19's impact on patients.

- Through funding from the Bill and Melinda Gates foundation, Drs. Mark Wurfel and Pavan Bhatraju have obtained funding for their project "COVID-19: Molecular determinants of clinical outcomes in COVID-19". The study hopes to better understand COVID-19 in pulmonary patients in the hospital.
- Drs. Mark Wurfel and Pavan Bhatraju have also obtained funding through the Centers for Disease Control Foundation for their project "Clinical Research Networks to Improve Clinical Management of Hospitalized COVID-19 Patients". The project will assess clinical management of in-hospital COVID-19 patients through collection of epidemiological and clinical data.

- Dr. Bryan Kestenbaum has received special funding from the National Institutes of Diabetes and Digestive and Kidney Diseases (NIDDK) to expand his current studies of kidney proximal tubular secretion. The project "Role of Kidney Proximal Tubular Secretion in Critical Illness" will test whether COVID-19 is associated with changes in tubular kidney function.
- Dr Jonathan Himmelfarb and the 'kidney on a chip' team have received funding from the National Center for Advancing Translational Sciences (NCATS/NIH) to study how the COVID-19 virus can infect kidney cells directly and affect their function.

The above projects have commenced or will soon. Many KRI investigators are looking for ways to further the scope of their current projects in order to study COVID-19. We hope that information learned from all studies will help kidney disease patients in the future.

