

## **National Diabetes and Digestive and Kidney Diseases (NIDDK) Advisory Council Meeting**

### **Division of Kidney, Urologic, and Hematologic Diseases Advisory Subcouncil Meeting May 12, 2022**

#### **Advisory Council KUH Subcommittee Members:**

Ms. Dawn Edwards (American Association of Kidney Patients)  
Dr. Christian Faul (University of Alabama at Birmingham) (Subject Matter Expert)  
Dr. Mark Nelson (University of Vermont)  
Dr. Keith Norris (University of California at Los Angeles)  
Dr. David Penson (Vanderbilt University)  
Dr. Kathleen Sakamoto (Stanford University)  
Dr. Ian Stewart (Commissioned Corps of the US Public Health Service)

#### **NIH/NIDDK/KUH Staff:**

Dr. Kevin Abbott	Dr. Jenna Norton
Dr. Julie Barthold	Dr. Van Nguyen
Dr. Eric Brunskill	Mr. Matt Oldham
Dr. Kevin Chan	Dr. Afshin Parsa
Ms. Emily Duggan	Ms. Aretina Perry-Jones
Ms. Shannon Givens-Bradley	Mr. Robert Pike
Dr. Daniel Gossett	Dr. Matt Portnoy
Dr. Raquel Greer	Dr. Tracy Rankin
Dr. Xiaodu Guo	Dr. Cindy Roy
Dr. Shilpa Hattangadi	Dr. Anna Sadusky
Dr. Jason Hoffert	Dr. Ivonne Schulman
Dr. Chris Ketchum	Ms. Neha Shah
Dr. Paul Kimmel	Ms. Aliecia Shepherd
Dr. Ziya Kirkali	Dr. Victoria Spruance
Dr. Karl Malik	Dr. Robert Star
Dr. Susan Mendley	Mr. Jonathan Teinor
Dr. Chris Mullins	Dr. Ken Wilkins
Dr. Deepak Nihalani	

#### **Welcome and Introductions**

Dr. Star welcomed council members and attendees to the 219<sup>th</sup> KUH subcouncil meeting. Dr. Norris led the motion to approve the meeting minutes from September subcouncil.

#### **Upcoming Meetings and Workshops**

Dr. Star noted several upcoming meetings and workshops and commented that this information was available on the ECB for future reference.

#### **FY24 Initiatives**

Councilors provided feedback for the following initiatives:

- Comprehensive Assessment of Renal function (COAR): Dr. Norris noted the issue of renal reserve is critical and added that there is a need to capture this from the clinical perspective as this can have a dramatic impact on the care of patients. Dr. Nelson suggested the need for easy, cheap, accessible tests. Additionally, measurements of brain function and other organs that impact the kidney may be helpful. Ms. Edwards queried if this initiative would assist clinicians in diagnosing patients earlier and more accurately in order to be able to fine tune the dosing of dialysis, which is in line with precision medicine. Dr. Parsa noted this proposal is geared toward refined measures for the kidney and will work on renal reserve in order to capture early disease. Dr. Star noted determining the right dosing for dialysis patients is challenging and added that this proposal is focused on early action but could assist in defining this area of need as well. Dr. Stewart noted better markers of GFR are needed and expressed enthusiasm that this proposal goes beyond GFR. Dr. Penson noted strong support for this initiative based on the previously used race-specific eGFR measurement and commented this could improve equity.
- Renewal of Advancing Clinical Research in Primary Glomerular Disease (Cure GN): Dr. Faul queried the connection between the Cure GN and NEPTUNE. Dr. Parsa noted some Cure GN investigators are also active in NEPTUNE and added that NEPTUNE participants who are close to Cure GN sites will be followed through Cure GN.
- Renewal of the United States Renal Data System (USRDS): Dr. Faul expressed strong support for this important initiative. Dr. Norris commented this is a valuable resource and noted that the USRDS is one of the best investments NIDDK has made. Ms. Edwards echoed Dr. Norris's comments about this valuable resource and how these findings impact current research. Ms. Edwards added that she uses this resource to teach patients how to use it in terms of advocacy. Additionally, she commented that she accesses the USRDS online rather than print out the hard copy for congressional use; however, she noted that physical document would be helpful for use at dialysis centers to educate patients.
- Extension of LURN (Symptoms of Lower Urinary Tract Dysfunction Research Network): Dr. Penson expressed strong support for this initiative, commenting that this extension is needed to provide meaningful information. He also noted that recruitment issues are common for this type of research study and not the fault of investigators. Dr. Nelson queried if enough participants are being recruited. Dr. Penson noted he serves on the External Experts Panel, and the investigators should be applauded for the careful sample size calculation. He emphasized that it is easier to recruit women with urgency issues than men due to the prevalence in this population. Dr. Kirkali noted that the study was also impacted by the COVID-19 pandemic, since the study aims to recruit patients seeking treatment and patients were reluctant to come to the hospital. Dr. Kirkali also noted more phenotyping efforts for urinary urgency in the extension period will lead to more targeted treatments for patients.
- Towards a Personalized Approach to BPH/LUTS: Connecting Molecular Pathology to Lower Urinary Tract Symptoms: Dr. Penson noted this is a significant research area and commented he is highly supportive, as this builds on the LURN study. While acknowledging that this is an important area of study, Dr. Penson expressed some concern that it may be difficult to obtain samples from non-surgical patients. Dr. Nelson echoed Dr. Penson's concern regarding the barrier of trying to obtain human samples. Dr. Kirkali commented that more details will follow once the workshop is held. Dr. Nelson also commented that underactive bladder male patients may be underreported; Dr. Kirkali agreed and noted that

this population will be represented and added that this initiative also focuses on new imaging techniques for all eligible patients.

- Clinical Trials to Inform Management of Urologic Chronic Pelvic Pain Syndrome Study (COMPASS): Dr. Penson noted strong support for research in this area and commented that this is a natural extension of the MAPP Network. Dr. Norris also expressed support for this initiative and commented that this is an important area of study.
- Renewal of UDA: Urologic Diseases in America (Epidemiology of Urologic Disease) UroEpi: Dr. Penson expressed low enthusiasm for using EHR to determine BPH as this has been unsuccessful in the past. Dr. Abbott noted this is an optional task in the current contract and it will be done using Optim data and noted that the contractor will approach the use of EHR data cautiously. Dr. Norris noted extracting data from EHR is challenging and commented this will require a thoughtful approach and suggested looking at several databases for validation and harmonization.
- Nuclear architecture and regulation of hematopoiesis: Dr. Roy noted this is a new topic for the existing SHINE network.
- Novel Software Tools to Identify New Pathways of Blood Disease Development using Existing Genomic Datasets: Dr. Norris noted this leverages an existing resource and commented that this initiative provides a forum for data scientists and hematology investigators and trainees to collaborate.
- KUH Training Coordinating Center: Fostering the AdvanceMent of an Inclusive Learning communitY (KUH FAMILY): Dr. Norris expressed enthusiasm for this concept, particularly as it can positively impact trainees who are at smaller academic research institutions. However, he also commented on the large time commitment that is demanded by coordinating center PIs and warned against overloading this center with too many functions. He added that the FOA should clearly outline information about coordination and evaluation. Dr. Star noted the FOA will keep the focus on trainees. Dr. Nelson expressed support for this initiative and queried how smaller institutions can handle mentoring challenges, particularly with no KUH-science focused colleagues at their institution. Dr. Spruance emphasized that the new U2C program focuses heavily on mentorship and added that this program is developing resources for this effort in addition to building peer to peer and mentorship networks. Dr. Nelson emphasized the need for near-peer mentors who are Associate Professors since they have just completed their first R01, rather than seasoned investigators. Dr. Faul queried how KUH will attract and retain trainees in these fields. Dr. Spruance noted all KUH initiatives are trying to address this through training outreach activities.
- KUH Summer Undergraduate Research Experience Program: Dr. Norris expressed enthusiasm for this program. Dr. Faul also commented on the importance of this program as a national resource.

### **KUH Closed Session**

Dr. Star commented on the importance of confidentiality during closed session. Council members approved several closed business items.