



# KIDNEY ACTION WEEK JUNE 6-10, 2022



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# KIDNEY ACTION WEEK 2022

## AGENDA

### MONDAY, JUNE 6TH

**2:00 PM** Welcoming Remarks from the American Kidney Fund

**2:30 PM** Home Dialysis: What to Know and What to Ask

Compared to in-center dialysis, home dialysis can provide people with end-stage renal disease (ESRD) with more flexibility, more food options and better health outcomes. However, despite its benefits, home dialysis usage in the U.S. is still relatively low. This session will feature home dialysis experts and patients who use home dialysis. Experts will address common myths about home dialysis and discuss how to explore dialysis and support options with your health care provider. Patients on the panel will openly share their experiences with home dialysis.

**4:00 PM** Clinical Trials: Why Your Participation Makes a Difference

Speakers will provide an overview of clinical trials and the importance of understanding patient rights as a clinical trial participant. Speakers will answer frequently asked questions about finding and enrolling in a clinical trial, informed consent, and why diverse representation in clinical trials is important to further ensure effectiveness of new drugs and treatment methods. Audience members will have the opportunity to submit questions to a nephrologist, a clinical trials study manager and a caregiver with extensive experience participating in clinical trials.

**5:30 PM** RE-BROADCAST : Home Dialysis: What to Know and What to Ask

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# TUESDAY, JUNE 7TH

## **11:30 AM** Ask the “Cooking Doc”: Q & A with Nephrologist, Dr. Blake Shusterman

Choosing the right foods is key to managing kidney disease at every stage. Whether you are on dialysis, were just diagnosed with kidney disease, have a kidney transplant or are somewhere in between, understanding what foods to eat and in what amount can help you successfully manage kidney disease.

Dr. Blake Shusterman, aka The Cooking Doc, will provide insights into eating well with kidney disease, combining his expertise as a practicing nephrologist and a published cookbook author. The Cooking Doc is bringing his “Change Your Buds” message to Kidney Action Week through an interactive question and answer session that will discuss common challenges of eating with kidney disease and offer strategies for eating within dietary guidelines, while still enjoying food.

## **1:00 PM** Congressional Briefing: The Crisis in Kidney Disease

From 2009-2019, the number of people with end-stage renal disease (ESRD) increased by more than 40 percent and that trajectory is predicted to continue over the next 10 years. In 2009, there were 574,000 people with kidney failure; that number increased to 809,000 in 2019; if this trend continues, the number of people with ESRD will be well over 1 million by 2030.

ESRD has a hugely disproportionate impact on communities of color; Black people comprise 13% of the US population but are over 35% of people on dialysis. We also know that COVID-19 has had a devastating impact on people with ESRD – mortality and hospitalization rates for these patients much higher than the general population. Further, ESRD not only disrupts lives, but it also has a high cost to society in terms of medical costs, lost wages and mortality. This briefing will examine WHY we are in this situation and WHAT we can do about it.

This session is made possible thanks to the generous support of the American Kidney Fund’s 2022 Corporate Members.

## **2:30 PM** Stage 3 CKD - High Blood Pressure and Kidney Disease

Only second to diabetes, high blood pressure (hypertension) is a top cause of chronic kidney disease (CKD). Speakers will discuss the impact of high blood pressure on the kidneys, how to manage high blood pressure with stage 3a and 3b CKD, the importance of healthy eating and physical activity, as well as medication treatment options. The audience will be able to ask questions of a nephrologist, a renal dietitian, and a speaker living with stage 3 CKD and high blood pressure.

## **4:00 PM** Life with In-Center Dialysis

The dialysis care team from Iredell Health System in Statesville, NC will provide an overview of in-center dialysis. The panelists acknowledge the fear and confusion that comes with a kidney disease diagnosis and will aim to give an easy-to-understand summary of dialysis, and also discuss social issues associated with dialysis, how to best communicate with your care team, and answers to common patient questions.

# TUESDAY, JUNE 7TH

## **5:30 PM** Veterans Health Administration (VHA) and American Kidney Fund Coffee Chat

As part of a partnership between the American Kidney Fund and the Veterans Health Administration, this talk will feature a conversation between LaVarne Burton (AKF) and Dr. Erica Scavella (VHA) about kidney disease and how it impacts the veteran population. More specifically, they will cover risk factors, causes, and treatments for CKD; share about health disparities in kidney disease generally and specifically for veterans; and provide resources for veterans at risk for kidney disease. By raising awareness around kidney disease and how it affects veterans, this session will illustrate the value of this important partnership around promoting the health and wellness of veterans.

# WEDNESDAY, JUNE 8TH

## **11:30 AM** Kidney Transplant - Navigating the Waitlist

The life-changing experience of receiving a kidney transplant all starts with the referral for evaluation. When considering a patient for a kidney transplant, the evaluation team considers the patient's physical health, mental health, and finances. In this session, the panelists will provide an overview of the transplant evaluation process, explain how this process can lead to inequities in who receives a transplant, and empower patients to take an active role in conversations with their health providers. This talk will be brought to life by a patient who has been through this process multiple times and can offer hope for patients considering this option.

## **1:00 PM** Stage 3 CKD - Diabetes and Kidney Disease

The "silent" nature of stage 3 chronic kidney disease (CKD) often leads to a delayed diagnosis, and subsequently delayed treatment. Because diabetes is the leading cause of CKD, individuals with diabetes should have their primary care provider regularly test them for kidney disease to ensure a timely diagnosis and treatment intervention to slow progression. Panelists will discuss diabetic kidney disease (DKD), ways to manage DKD through testing, medicine, and working with a dietitian. In addition, one of the panelists brings the perspective of living with DKD and will share his experience and changes he made to his lifestyle that made a difference.

This session is made possible thanks to generous support from Boehringer Ingelheim/Lilly.

## **2:30 PM** The Past, Present and Future of Testing for Kidney Disease

With all the changes in kidney disease testing over the years, it can be unclear which tests provide the most accurate diagnosis. In this session, the panelists will be providing an overview of the landscape of kidney disease testing from the past, present, and future. The panelists will review the most common tests used to date (UACR and eGFR) and discuss the issues associated with each. In addition, the panelists will highlight recent changes to the eGFR equation and will discuss the future of kidney disease testing (cystatin-C, biomarkers, etc.). The goal of this session will be to bring awareness to the changes in kidney disease testing to empower the public to advocate for the test that is best for them.

# WEDNESDAY, JUNE 8TH

## **4:00 PM** We All Should Care About APOL1-Mediated Kidney Disease

The Apolipoprotein L1 (APOL1) gene is part of the APOL gene family, which plays a role in innate immunity, our body's built-in system to fight threats. In some individuals, this gene has evolved to protect against a parasite that causes African human trypanosomiasis (African sleeping sickness); unfortunately, this protection against one disease has also been shown to cause significant kidney damage in some. Today, people of African ancestry all around the world may carry these APOL1 variations, including people who identify as African American, Afro-Caribbean and Latino/Latina.

Having two variations in the APOL1 gene is associated with increased risk of kidney disease and even kidney failure, so it's important to understand your genotype and whether you are at increased risk of kidney disease. For those who have APOL1-mediated kidney disease (AMKD), early detection can help patients and their physicians choose appropriate treatment, identify potential risk to other family members, and prepare for more rapid disease progression.

In this session, panelists will provide an overview of the APOL1 gene and how an individual's ancestry may play a role in how the gene affects certain populations, especially those of African and Afro-Latin ancestry. Panelists will discuss genetic testing options (how to find out if you have this genetic variant) and how a patient's life may be affected by a positive APOL1 genetic test result.

This session is made possible thanks to the generous support from Vertex Pharmaceuticals Inc.

## **5:30 PM** RE-BROADCAST : The Past, Present and Future of Testing for Kidney Disease

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# THURSDAY, JUNE 9TH

## **11:30 AM** Health Insurance and the Impact of Kidney Disease on Finances

Living with kidney disease can present many financial constraints due to increased expenses associated with purchasing healthier food, medicines, and treatments, despite Medicare coverage. Panelists will provide an overview of ESRD Medicare eligibility, highlight out-of-pocket costs associated with dialysis and transplant, and links to resources available to assist patients through what can be an overwhelming time.

# THURSDAY, JUNE 9TH

## **1:00 PM** COVID-19: Returning to Normal for the Immunocompromised

While many people may experience mild to moderate COVID-19 symptoms, people living with kidney disease or a transplant are at a higher risk of becoming severely ill with COVID-19. Dr. Robert Montgomery and Dr. Sapna Mehta will give an overview of monoclonal antibodies and how they can be used in addition to the COVID-19 vaccines. Dr. Montgomery and Dr. Mehta will also speak about what 'return to normal' means for individuals who are immunocompromised and what all of us can do to help protect those who are the most vulnerable to COVID-19.

## **2:30 PM** ADPKD: How to Work with Your Doctor, Talk to Your Family and Find Support

Autosomal dominant polycystic kidney disease (ADPKD) is a genetic condition that causes clusters of cysts to grow on the kidneys. Most people who have ADPKD eventually see the disease progress into kidney failure, requiring dialysis or a kidney transplant.

In this session, speakers will provide an overview of ADPKD – including diagnosis, prognosis, treatment and management. Session discussions will focus on the importance of managing ADPKD at each stage, ways to start conversations with health care providers and family members, as well as how to find support and resources.

This session is made possible thanks to the generous support from Otsuka America Pharmaceutical, Inc.

## **4:00 PM** All About Kidney Stones - Causes, Types, Treatment and Prevention

Kidney stones are a common problem, affecting over half a million people every year. One in 10 people will have a kidney stone at some point in their lives, and about 80 % of those stones will be the calcium oxalate type.

In this session, our panelists will give an overview of what a kidney stone is, its signs and symptoms and common risk factors. Our panelists will also describe the multiple types of stones and how finding out which type of stone you have may help improve your treatment options and prevention strategies.

Participants will leave with a better understanding of kidney stones that will empower them to speak with their health care providers, especially if they have already experienced frequent or multiple kidney stones.

This session is made possible thanks to the generous support from Alnylam Pharmaceuticals.

## **5:30 PM** RE-BROADCAST : The Past, Present and Future of Testing for Kidney Disease

With all the changes in kidney disease testing over the years, it can be unclear which tests provide the most accurate diagnosis. In this session, the panelists will be providing an overview of the landscape of kidney disease testing from the past, present, and future. The panelists will review the most common tests used to date (UACR and eGFR) and discuss the issues associated with each. In addition, the panelists will highlight recent changes to the eGFR equation and will discuss the future of kidney disease testing (cystatin-C, biomarkers, etc.). The goal of this session will be to bring awareness to the changes in kidney disease testing to empower the public to advocate for the test that is best for them.

# FRIDAY, JUNE 10TH

## **11:30 AM** Veterans, Kidney Disease and Diabetes: The Mounting Mental Health Burdens of Managing Chronic Diseases

Prevalence of chronic kidney disease among the veteran population is estimated to be 34% higher than the general population. Panelists will discuss the unique experience of veterans living with kidney disease along with a general background on kidney disease and its two leading risk factors: high blood pressure and diabetes. The panelists hope to stimulate a thought-provoking discussion regarding the mental health burdens veterans face when confronted with diagnoses of chronic medical conditions such as kidney disease and diabetes. Additionally, solutions to facilitating mental health care will be explored.

## **1:00 PM** Understanding IgA Nephropathy (IgAN)

IgAN is a type of autoimmune disease that starts in the gut and over time, causes damage to the kidneys. Although testing urine for protein can indicate IgAN nephropathy, a kidney biopsy is the only test that give doctors an accurate diagnosis. Panelists will start with an overview of IgA nephropathy (IgAN), then discuss its various treatment approaches for managing IgAN, including proper eating, ACEs/ABRs and new and emerging medicines. The panelists will also highlight patient resources offered by the IgAN Foundation of America, including its patient registry.

This session is made possible thanks to the generous support from Calliditas Therapeutics.

## **2:30 PM** What is Hyperkalemia? - Treatment and Management

Hyperkalemia (high potassium) is a serious problem and often a complication of advanced kidney disease. Hyperkalemia is a higher-than-normal level of potassium in the blood. Although mild cases may not cause symptoms and may be easy to treat, severe cases of hyperkalemia that are left untreated can lead to abnormal heart rhythms or even death. While hyperkalemia can be managed somewhat by eating low-potassium foods, there are important medicines available that effectively manage this condition. Our panelists will give an overview of hyperkalemia, discuss treatments, and highlight the various no-cost hyperkalemia management resources featured on AKF's Kidney Kitchen® and our Beyond Bananas™ campaign.

This session is made possible thanks to the generous support from AstraZeneca.

## **4:00 PM** My Journey Living with Kidney Disease: Patient Perspectives

Experiences living with chronic kidney disease (CKD) vary from person to person. While some receive a diagnosis at an earlier stage, many do not, resulting in a delayed diagnosis, kidney failure and a "crash" into needing dialysis. The panelists will be sharing their individual stories about how they navigated their kidney disease journey. They will cover experiences with dialysis, transplant, and making lifestyle changes to slow the progression of CKD. There are so many decisions along the journey and this session highlights multiple perspectives and shows how these decisions impact loved ones as well.

## **5:00 PM** Closing Remarks from the American Kidney Fund

Each day will also feature a cooking demonstration, tips on how to manage stress and mental health, fitness demonstrations, and more!

**Save your spot today at**  
**[www.KidneyActionWeek.org](http://www.KidneyActionWeek.org)**



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