

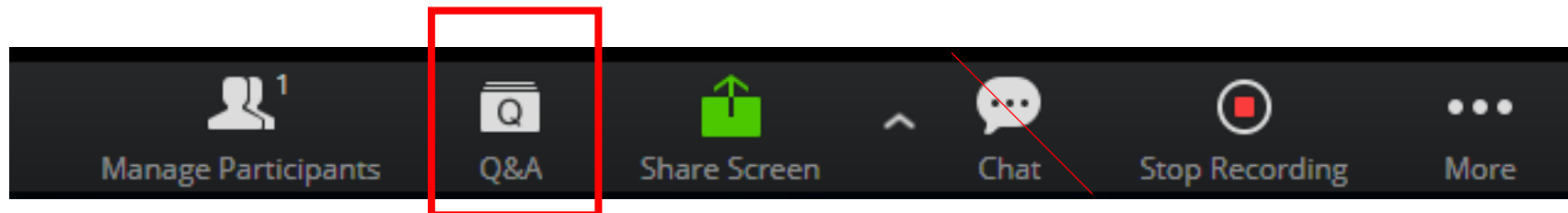


Panel Discussion: Introducing the Unknown Causes of Kidney Disease Roadmap

July 27, 2021

Technical Overview

- Please stay on **'mute'** throughout the duration of the webinar.
- The chat box has been disabled.
- If you have questions for the speaker or for the AKF team:
 - Please type it into the **Q&A box** in your control panel.
 - We will answer questions out loud during the Q&A portion of the presentation.



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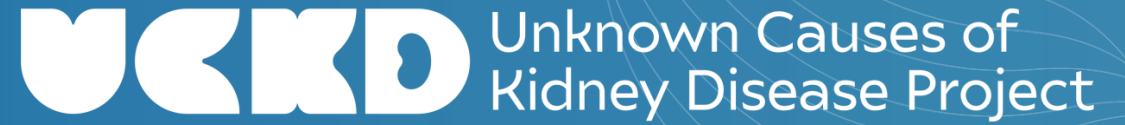
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LaVarne A. Burton

President and CEO, American Kidney Fund



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Today's Panelists



**Julie Wright Nunes,
MD, MPH**
University of Michigan



Theresa Caldron
Rare kidney disease
advocate



**Trudy McKanna,
MS, CGC**
Natera



Holly Bode
American Kidney Fund

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For 50 years, AKF has put patients first



1971

AKF is founded



1980

First national kidney disease awareness campaign



1988

Clinical Scientist in Nephrology Program launched



1996

Free screening program begins



1997

Health Insurance Premium Program established



2003

First 4-star rating from Charity Navigator



2015

Named Consumer Reports top health charity



2020

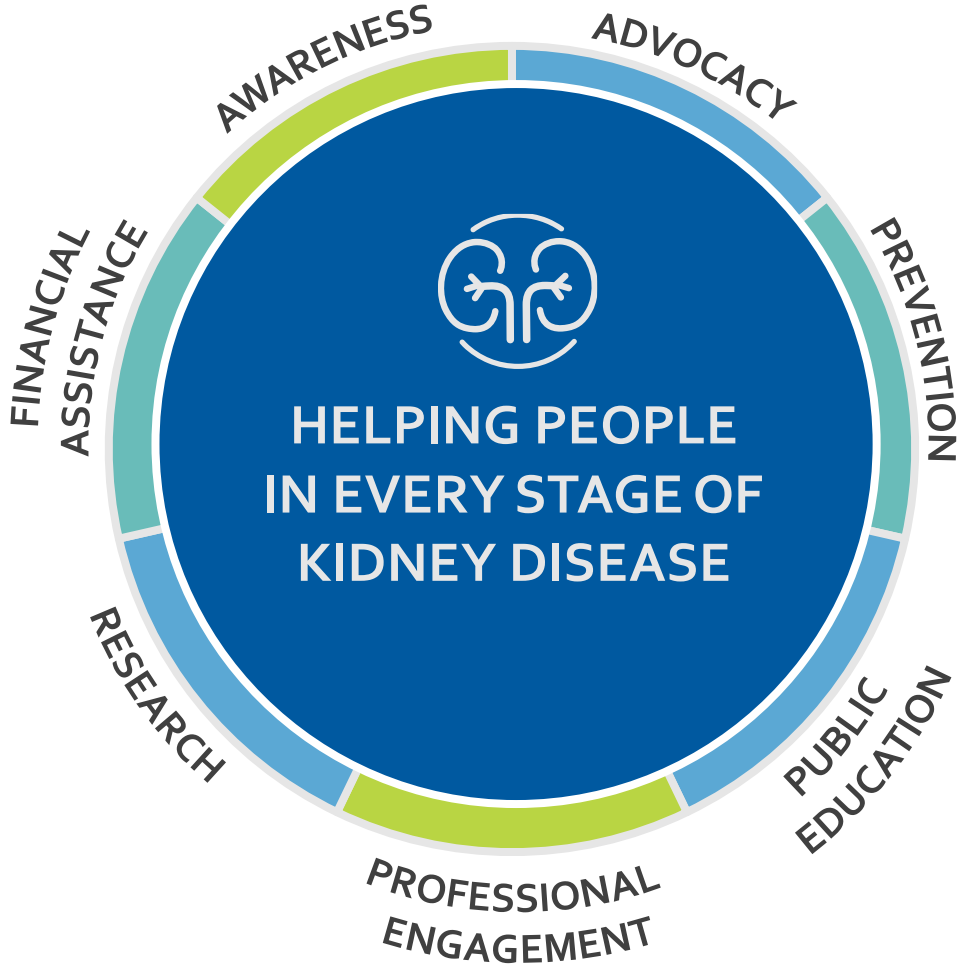
Launched the Unknown Causes of Kidney Disease Project

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Fighting on All Fronts



-  **AWARENESS**
-  **ADVOCACY**
-  **PREVENTION**
-  **PUBLIC EDUCATION**
-  **PROFESSIONAL ENGAGEMENT**
-  **RESEARCH**
-  **FINANCIAL ASSISTANCE**

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AKF's Insights into Unknown Causes of CKD

- AKF maintains one of the largest databases of patients with kidney failure in the United States
 - 1 in 6 dialysis patients
 - Primarily made up of people from communities of color (68.8%)
 - 100+ of which transition to transplant each month (1,615 in 2020 alone)
- In early 2018, the system was updated to improve user experience and to allow for tracking information important to patient outcomes.
- With this information, we can gain insight into where patients need our help the most.

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AKF's Insights into Unknown Causes of CKD

- For many patients in kidney failure, their income and savings are drastically affected by their diagnosis
- As many as 1/3 of dialysis patients did not see a nephrologist in the year leading up to their onset of kidney failure, meaning many “crashed” into dialysis without warning.
 - In these cases, patients often are suddenly unable to work and maintain their insurance
 - This leads to bills and out-of-pocket medical expenses compounding quickly
- Average annual household income for a patient AKF serves with its Health Insurance Premium Program was \$24,299 in 2020 and the vast majority are upside down in their monthly income vs. expenses.

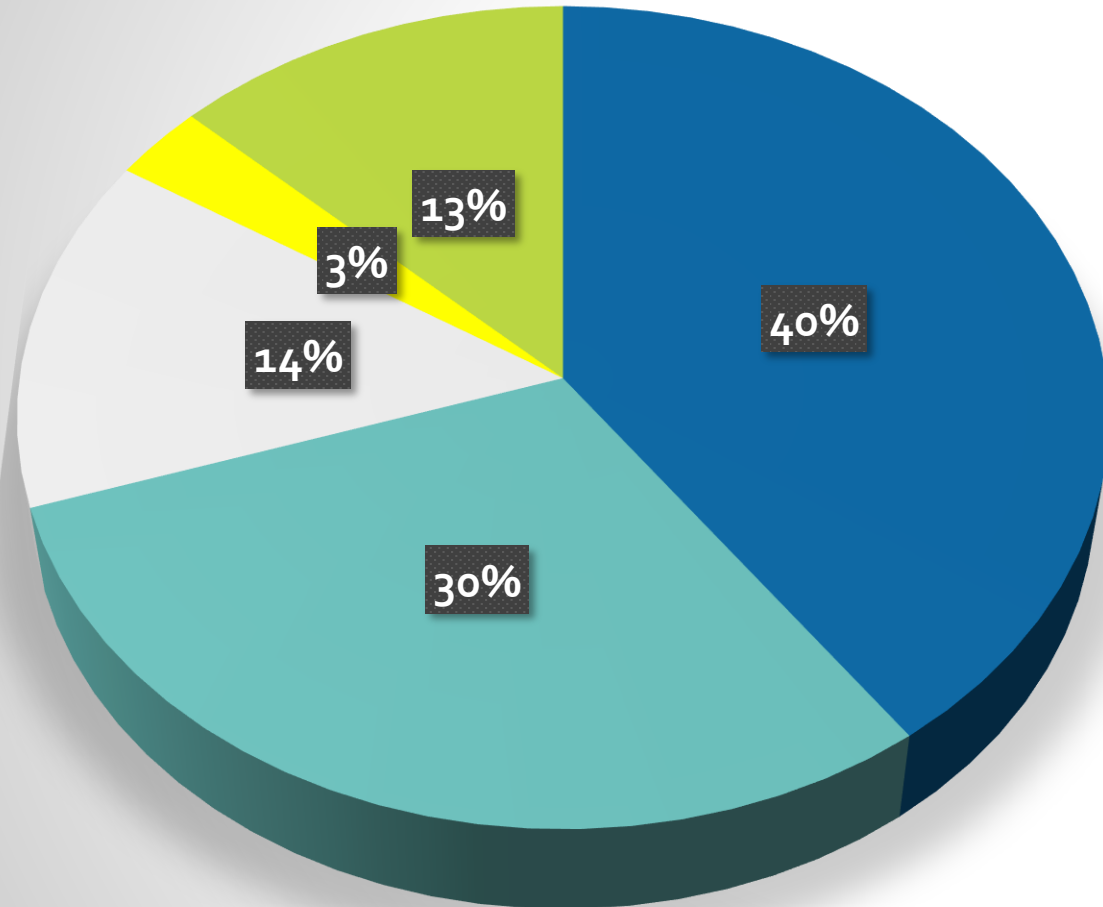


- DIABETES
- HIGH BLOOD PRESSURE
- GLOMERULONEPHRITIS
- OTHER
- UNKNOWN

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Primary Cause of Kidney Failure of Patients in AKF's Grants Management System (2019)



- Diabetes
- High blood pressure
- Unknown
- Polycystic kidney disease (PKD)
- All other causes combined

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ISSUE	GOAL	RESULTS
<p>Kidney patients understandably want a definitive diagnosis to what caused their late-stage CKD or kidney failure—sometimes it cannot be found, but there may be evolving areas of care that can provide benefits.</p>	<p>The Summit’s goal was to bring together researchers, patient advocates, advocacy organizations, government agencies and industry to identify how the kidney community can drive innovation in research, diagnosis and treatment of the underlying causes of kidney disease.</p>	<p>On December 1, 2020, AKF convened more than 100 stakeholders to review the research on this subject, discuss other available or potential data sets, identify any barriers to progress, and develop a plan for a path forward to address this serious issue in nephrology.</p> <p>The Summit’s findings, along with background research and interviews were used to create the Roadmap being released today.</p>

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Roadmap to Change

- The Roadmap released today provides the nation with a consensus document for addressing unknown causes of kidney disease.
- It has an in-depth discussion as brought forth at the Summit of the existing barriers that exist and provides short, mid and long-term steps for giving patients a better picture of what caused their kidney disease.
- <https://www.kidneyfund.org/uckd>



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Barriers to Change: Panel Discussion

Some of the barriers identified in the Roadmap include:

- Patients getting a late diagnosis of kidney disease
- Potential that a confirmatory diagnosis won't change treatment
- Possible lack of adequate insurance coverage, especially in relation to genetic testing
- Lack of awareness and perhaps well-established, evidence-based information to guide genetic testing
- Communication barriers between patients and healthcare professionals about kidney disease in general

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Recommended Solutions: Panel Discussion

The overarching solution areas in the Roadmap include:

- Advocating for widespread and equitable insurance coverage of tests to help understand and diagnose kidney disease, including current and future tests related to genetics.
- Increasing providers' interest and awareness about the range of possible root causes of kidney disease through education and incentive structures.
- Educating patients about kidney disease and testing in an effective, culturally competent way and empowering them to advocate for an accurate diagnosis.
- Based on evidence available, encouraging the development of national standards related to when and how genetic testing can be useful and applied.

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Next Steps

- AKF is committed to seeing these changes through and has already assembled three implementation groups to begin work on this project. These groups will each focus on one of these three areas:
 - Public Policy
 - Patient and Caregiver Empowerment
 - Healthcare Professional Awareness and Education



Questions for our Panel

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