

## New Era for Preventing End-Stage Kidney Disease Act of 2023 (H.R 6790)



There are 37 million Americans with kidney disease—including rare kidney disease—and most people do not know they have it. There are about 150 rare kidney diseases.<sup>1</sup> There are no FDA-approved treatments for most rare kidney diseases, and many patients struggle to receive an accurate diagnosis and expert treatment. These treatment and diagnostic barriers, coupled with the lack of rare kidney disease awareness and education, often cause a delay in diagnosis. This delay can result in a rapid decline in kidney function and, ultimately, kidney failure, when the only options are dialysis, transplant or death.

Each day in the United States, on average, 340 people begin dialysis<sup>2</sup> and 13 people die waiting for a kidney transplant.<sup>3</sup> In 2019, Medicare spent a total of \$124 billion on chronic kidney disease (CKD) and ESRD.<sup>4</sup> Additionally, communities of color are disproportionately affected by rare kidney diseases and a lack of adequate treatment options due to existing health disparities — Black Americans are 4-5 times more likely to develop kidney failure than white Americans.

To address rare kidney disease in the United States, we need more research, public awareness, shorter times to diagnosis, access to genetic testing and counseling, additional treatments, and understanding of why rates of kidney disease are higher in underserved communities. These steps would help assuage the burden of rare kidney disease on individuals and help defray costs of dialysis and kidney care in the Medicare program.

The New Era for Preventing End-Stage Kidney Disease Act of 2023 (H.R. 6790 ), introduced by

Congressman Gus Bilirakis and Congresswoman Terri Sewell, aims to improve the understanding and timely and accurate diagnosis of rare kidney diseases.

<sup>1</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6685068/>

<sup>2</sup> <https://www.cdc.gov/kidneydisease/basics.html>

<sup>3</sup> <https://unos.org/media-resources/releases/over-30-kidney-donors-and-advocates-to-celebrate-world-kidney-day-from-the-top-of-mount-kilimanjaro/#:~:text=Roughly%2013%20people%20die%20each,as%2075%20through%20tissue%20donation.>

<sup>4</sup> <https://www.cdc.gov/kidneydisease/basics.html>

## **NIDDK Centers of Excellence on Rare Kidney Disease Research**

- Create Centers of Excellence at NIDDK to study the causes, diagnosis, progression, and treatment of rare kidney diseases and increase public awareness of rare kidney diseases, particularly in rural and underserved communities.
- The Centers will develop resources for clinical research, training, diagnosis, prevention and treatment of rare kidney diseases.

## **HHS Study and Report on Rare Kidney Disease**

- The Secretary of the Department of Health and Human Services (HHS) will submit a study to Congress focused on understanding and slowing the progression of rare kidney disease through early intervention, testing and treatment.
- The study will examine the quality and reliability of kidney biopsies and the use of genetic tests, including the use of genetic and genomic tests in detecting the APOL1 gene. The study will also include the social, behavioral, and biological factors leading to rare kidney disease, such as access to nephrologists among communities that are disproportionately affected.

## **Training Primary Care Providers and Expanding Nephrology Fellowships**

- Funding to schools of health professions to expand primary care training to include rare kidney disease.
- Increase the number of nephrology fellowships aimed at expanding the knowledge about rare kidney disease prevention, diagnosis, and treatment of for populations disproportionately impacted by the disease, including the prevalence of the APOL1 gene.

## **Evaluation of Methods Used to Delay Kidney Disease**

- The Secretary of the HHS provide a study to Congress that will include an evaluation of methods for treating rare kidney disease, especially those that delay or eliminate the need for transplant and dialysis. The study will also review efforts to increase public awareness of rare kidney disease.
- The report will include recommendations for legislative changes that would make progress on the goals identified in the study.