

New Era for Preventing End-Stage Kidney Disease Act of 2023



Issue:

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

Each day in the United States, 360 people on average begin dialysis² and 13 people die waiting for a kidney transplant.³ In 2019, Medicare spent a total of \$124 billion on chronic kidney disease (CKD) and end stage renal disease (ESRD, or kidney failure)⁴ 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 times more likely to develop kidney failure than white Americans.

To address rare kidney diseases in the United States, we need more research, public awareness, earlier diagnosis, access to genetic testing and counseling, additional treatments and improved 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 (HR 6790), introduced by Reps. Gus Bilirakis and Terri Sewell, aims to improve understanding and timely and accurate diagnosis of rare kidney diseases.

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

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

³ <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%202013%20people%20die%20each,as%2075%20through%20tissue%20donation.>

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

National Institute of Diabetes and Digestive and Kidney Diseases (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 Diseases

- 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 diseases 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 APOLI gene. The study will also include the social, behavioral and biological factors leading to rare kidney diseases, such as access to nephrologists among communities that are disproportionately affected.

Training Primary Care Providers and Expanding Nephrology Fellowships

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

Evaluation of Methods Used to Delay Kidney Disease

- The Secretary of the HHS will 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 diseases.
- The report will include recommendations for legislative changes that would make progress on the goals identified in the study.