New Era of Preventing End-Stage Kidney Disease Act

THERE IS NO CURE FOR KIDNEY DISEASE AND MOST PATIENTS LIVING WITH KIDNEY DISEASE FACE BARRIERS TO PRECISE DIAGNOSIS, SPECIALIZED CARE, AND EFFECTIVE TREATMENTS.

Chronic Kidney Disease vs. Rare Kidney Disease

Chronic kidney disease (CKD) and rare kidney disease (RKD) are two types of kidney disease affecting millions of patients that can lead to progressive, irreversible damage and the need for dialysis and/or kidney transplant.

Chronic Kidney Disease (CKD)

If left untreated, patients with CKD experience gradual damage to their kidneys leading to lossof kidney function that may cause them to lose their ability to filter waste and fluid in their blood. About 5% of CKD patients progress to end-stage kidney disease (ESKD).[1]

Rare Kidney Disease (RKD)

RKDs have low patient incidence and often have unidentified causes. RKDs are defined by a persistent and aggressive decline of the kidneys that lead to the need for complex medical care. Up to 50% of patients with RKD will progress to ESKD.[2]

The Patient Impact & Economic Cost of Kidney Disease

Top 10

Leading causes of death in the U.S. include kidney disease.[3]

150

Different rare kidney diseases, including Focal segmental glomerular sclerosis (FSGS).[4]

5X

The incidence of FSGS is around 5 times higher in Black patients when compared to white patients.[5]

$124.5 B

The annual cost for Medicare to treat kidney failure, which is driven by rare and chronic kidney disease.[6]

The New Era of Preventing End-Stage Kidney Disease Act

To address these gaps in kidney care, Reps. Gus Bilirakis (R-FL) and Terri Sewell (D-AL) introduced the New Era of Preventing End-Stage Kidney Disease Act (New Era Act), bipartisan federal legislation to improve outcomes and quality of life for hundreds of thousands of Americans living with rare kidney disease (RKD) and their families.

Reduce Kidney Failure

Close the Gap for Underserved Communities

Advance Research & Standard of Care

Improve Health Provider Education

Empower Patients & Communities

CONGRESS: Support the New Era Act

Congress must prioritize and advance the New Era Act to improve diagnosis and treatment for RKD and delay or eliminate the need for dialysis and transplant. By advancing this legislation, Congress can help to save lives, improve care for RKD patients, and reduce taxpayer costs.

Sources

1. National Library of Medicine. *"Chronic Kidney Disease and the Risk of End-Stage Renal Disease versus Death."* September 10, 2011.
2. National Library of Medicine. *"Chronic Kidney Disease and the Risk of End-Stage Renal Disease versus Death."* September 10, 2011.
3. Center for Disease Control and Prevention. *"Leading Causes of Death."* January 18, 2023.
4. Health Match. *"What Are Rare Kidney Diseases."* November 7, 2022.
5. Amir Shabaka, Ana Tato Ribera, Gema Fernandez-Juarez, *Focal Segmental Glomerulosclerosis: State-of-the-Art and Clinical Perspective*, Nephron, July 28, 2020.
6. Center for Disease Control and Prevention. *"Chronic Kidney Disease Basics."* February 2022.