



National
Kidney
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May 28, 2019

The Honorable Chuck Grassley
Chairman, Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Ron Wyden
Ranking Member, Senate Finance Committee
219 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Grassley and Ranking Member Wyden,

The National Kidney Foundation (NKF) is writing to express our strong support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI) and to request that, as part of the reauthorization, Congress consider the recommendations outlined below that will enable PCORI to continue to fulfil its critically important patient-centric mandate.

NKF is the largest, most comprehensive, and longstanding organization in the United States dedicated to the awareness, prevention and treatment of kidney disease. NKF serves hundreds of thousands of healthcare professionals, millions of patients and their families, and tens of millions of Americans at risk. NKF is the voice for patients, family members, and caregivers impacted by kidney disease. We share PCORI's commitment to generating high-quality, evidence-based research that supports patients, family members, caregivers, and health professionals, in making healthcare decisions that reflect patients' needs, preferences, and desired health outcomes.

Since its creation in 2010, PCORI has supported more than 600 research-related projects in high impact areas such as cardiovascular disease, prostate cancer, opioid prescribing, and type 2 diabetes management. By requiring that studies engage patients at all stages of the research process, PCORI-supported studies generate data that are more relevant to patients and those who care for them, and more feasible to implement in clinical practice. PCORI-supported studies provide invaluable information that will save our health care system significant expenditures by empowering patients to choose

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treatments that work best and, by doing so, limiting adverse events such as hospitalization and multiple courses of treatment.

For the kidney community (patients, family members, caregivers, healthcare professionals, payers, government, and other stakeholders), PCORI is having an impact on the lives of approximately 30 million Americans living with the disease, including the 115,000 patients who will develop complete kidney failure each year. Chronic kidney disease is a tremendous burden for patients and the healthcare system. PCORI is helping to address this public health crisis through the support of 18 kidney comparative effectiveness studies to help patients, their families, and their providers make better-informed decisions. For example, results from a study to test interventions that improve patient access to kidney transplant may improve health outcomes for end-stage renal disease (ESRD) patients and thus reduce overall healthcare spending.

NKF strongly encourages Congress to reauthorize PCORI and in doing so, to consider the following recommendations that we believe are essential to furthering PCORI's patient-centric research mission.

Reauthorize PCORI and its current funding mechanism for at least an additional 10 years

Stability in PCORI funding is imperative for the ongoing investment in PCORI-supported research to be most impactful. Research is a long-term endeavor, and some high quality CER studies can take 4-5 years to complete. Stable funding will allow for ample time to conclude studies, disseminate the findings, develop implementation tools, and drive implementation where appropriate. Reaffirming the commitment to PCORI for another 10 years will allow the institute to build on its success in changing the culture of research to be more patient-centric, and to enhance its work in partnership with other agencies and stakeholders to support a sustainable infrastructure for disseminating and implementing research outcomes meaningfully into practice.

Continue to exclude cost-effectiveness and extend the exclusion quality-adjusted life years from PCORI-supported studies

NKF believes the reauthorization legislation should continue to specifically prohibit PCORI from conducting cost-effectiveness analyses. NKF supports PCORI's view of cost-

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effectiveness research, namely that it is not an outcome of direct importance of patients. NKF further requests that Congress exclude quality-adjusted life years (QALY) as a potential outcome evaluated by PCORI-supported studies. QALY is not a patient-centric metric and patients have a long history of opposing its use in health research. By assigning value to perfect health, QALY leads to bias and discrimination against patients with chronic conditions and/or disabilities in seeking access to care that may improve their quality of life.

NKF applauds PCORI's ongoing efforts to support promising interventions that bring together patients and those who care for them to engage in meaningful research that can improve patient outcomes while improving the efficiency of the healthcare system. **Unless Congress acts, however, all this work will cease at the end of September 2019.**

NKF looks forward to engaging with you throughout the reauthorization process. Thank you considering our recommendations.

Sincerely,

Kevin Longino

Kevin Longino
CEO and Transplant Patient

Holly Mattix-Kramer

Holly Mattix-Kramer, MD
President

cc: The Honorable Bill Cassidy
The Honorable Mark Warner
The Honorable Shelley Moore Capito
The Honorable Chris Van Hollen