October 22, 2019

The Honorable Mark Warner  
United States Senate  
703 Hart Senate Office Building  
Washington, DC 20510  

The Honorable Bill Cassidy, MD  
United States Senate  
520 Hart Senate Office Building  
Washington, DC 20510  

The Honorable Chris Van Hollen  
United States Senate  
110 Hart Senate Office Building  
Washington, DC 20510  

The Honorable Shelley Moore Capito  
United States Senate  
172 Russell Senate Office Building  
Washington, DC 20510

Dear Senators Warner, Cassidy, Van Hollen, and Capito,

On behalf of the Friends of PCORI Reauthorization, we are writing to express our appreciation for your continued support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI).

The Friends of PCORI Reauthorization is a coalition of 183 patient and family caregiver organizations, health provider associations, biopharma/life science companies, payers, and other interested entities and individuals supportive of PCORI reauthorization. In particular we laud you for including in your discussion draft of the “Patient Centered Outcomes Research Institute Reauthorization Act of 2019” a 10-year reauthorization, maintenance of the current funding mechanisms, and continuation of the mandate to conduct comparative clinical effectiveness research (CER). As you consider additional policy changes, we also hope that you will give priority consideration to the comments that will be provided by individual stakeholders engaged in Friends of PCORI Reauthorization given their strong interest in maintaining PCORI’s patient-centered mission and diverse stakeholder input.

Support for a ten-year reauthorization of PCORI and its current funding mechanism is a long-term endeavor, and some high quality CER studies can take 4-5 years to complete. Even after the completion of these studies, additional time is needed to develop and implement clinical decision support and shared decision-making tools. For the ongoing investment in PCORI-funded research to be most impactful, stability in PCORI funding is imperative to allow ample time to conclude studies, disseminate the findings, develop implementation tools, and drive implementation where appropriate. Reaffirming a long-term commitment to PCORI’s patient-centered mission will allow the Institute to build on its success in changing the culture of research, and will enhance its work in partnership with other
agencies and stakeholders to support a sustainable infrastructure for disseminating and implementing research outcomes in a manner that improves healthcare decision-making between patients and their providers.

Support for maintaining PCORI’s mandate to conduct comparative clinical effectiveness research
High-quality, evidence-based care is crucial to reducing costs in the healthcare system. PCORI is the only research organization dedicated to funding studies that compare care approaches to determine what works best, for whom, and under which circumstances. By providing feedback on what care is going to provide the best result to each patient, PCORI is generating invaluable information that will save our health care system significant expenditures by empowering patients to choose treatments that work best and therefore limit adverse events such as hospitalization and multiple courses of treatment.

Among PCORI’s signature achievements in its first 10 years has been the creation of a new paradigm for conducting research that better integrates patient perspectives. PCORI uniquely funds patient-centered outcomes research that engages patients throughout the research process, including in the research design, so that it captures outcomes that matter to patients to improve health care decisions. PCORI research provides a wealth of valuable data for patients and health care providers, while also informing how the health care system can be more efficient. This outcome is driven currently by giving diverse stakeholders a voice and a vote on the Board of Governors, including patients.

We have advised our members that it is vitally important to also provide comments to you on the additional policy changes that are proposed in the discussion draft, particularly on their potential implications for advancing PCORI’s patient-centered mission and diverse stakeholder input. We appreciate your leadership to achieve a long-term, fully-funded reauthorization of PCORI and look forward to working with you throughout the legislative process to ensure PCORI remains patient-centered.

Sincerely,

The Honorable Tony Coelho
Chairman
Partnership to Improve Patient Care

The Honorable J. Phillip Gingrey, MD
Senior Advisor
District Policy Group

Enclosure

cc: The Honorable Chuck Grassley
The Honorable Ron Wyden
National Organizations
(183 Members)

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Healthcare Research Associates
Heart Valve Voice US
Hydrocephalus Association
Infectious Diseases Society of America
International Cancer Advocacy Network
International Foundation for Gastrointestinal Disorders
International Pemphigus and Pemphigoid Foundation
Interstitial Cystitis Association
Janssen Pharmaceuticals
Johns Hopkins University and Medicine
Lakeshore Foundation
Latinos Against Alzheimer’s
Livpact
Louisiana Public Health Institute
Lung Cancer Alliance
Lupus and Allied Diseases Association Inc.
Lymphatic Education & Research Network
March of Dimes
Mended Hearts
Men’s Health Network
Merck
Moffitt Cancer Center
Muscular Dystrophy Association
Muslims for Evidence Based Healthcare
My Epilepsy Story (MES)
National Alliance of Healthcare Purchaser Coalitions
National Alliance on Mental Illness
National Alopecia Areata Foundation
National Ataxia Foundation
National Blood Clot Alliance
National Eczema Association
National Fibromyalgia and Chronic Pain Association
National Hispanic Medical Association
National Kidney Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Pancreas Foundation
National Partnership for Women & Families
National Psoriasis Foundation
NEC Society
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NephCure Kidney International
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No Health Without Mental Health
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Scleroderma Foundation
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Society for Medical Decision Making
Society of General Internal Medicine
Society of Teachers of Family Medicine
Solve ME/CFS Initiative
Stanford School of Medicine
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The Coalition to Transform Advanced Care
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The Larner College of Medicine
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The Myositis Association
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The Sturge-Weber Foundation
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U.S. COPD Coalition
U.S. Hereditary Angioedema Association
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Virginia Commonwealth University
Wake Forest School of Medicine
Weill Cornell Medicine