



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

Research 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)

AcademyHealth	American Gastroenterological Association
Access to Integrative Medicine Health Institute	American Heart Association
Alliance for Aging Research	American Liver Foundation
American Academy of Family Physicians	American Medical Information Association
American Academy of Neurology	American Multiple Endocrine Neoplasia Support
American Academy of Sleep Medicine	American Occupational Therapy Association
American Academy of Pediatrics	American Parkinson Disease Association
American Association for Cancer Research	American Society for Transplantation and Cellular Therapy
American Association for Respiratory Care	American Society of Hematology
American Association for the Study of Liver Diseases	American Society of Nephrology
American Association of Colleges of Pharmacy	American Thoracic Society
American Association of Neurological Surgeons and Congress of Neurological Surgeons	American Urological Association
American Association of Nurse Practitioners	America's Essential Hospitals
American Association on Health and Disability	Arthritis Foundation
American Chiropractic Association	Associated Medical Schools of New York
American College of Physicians	Association for Clinical and Translational Science
American College of Surgeons	Association for Community Affiliated Plans
American Diabetes Association	Association of American Medical Colleges
	Association of American Universities
	Association of Departments of Family Medicine

Association of Family Medicine Residency Directors

Association of Pathology Chairs

Association of Public and Land-grant Universities

Association of Rehabilitation Nurses

Association of Schools and Programs of Public Health

Association of University Centers on Disabilities

Asthma and Allergy Foundation of America

Autism Speaks

Better Medicare Alliance

Blue Faery: The Adrienne Wilson Liver Cancer Association

Bobby Jones Chiari & Syringomyelia Foundation

Brain Injury Association of America

BrightFocus

Cancer Support Community

Cedars-Sinai

Celiac Disease Foundation

Center for Endometriosis Care

Cholangiocarcinoma Foundation

Cincinnati Children's Hospital

Clinical Research Forum

Coalition for Clinical and Translational Science

COPD Foundation

Council of Academic Family Medicine

CreakyJoints (Global Healthy Living Foundation)

Creighton University School of Medicine

Crohn's & Colitis Foundation

Cure HHT

Dartmouth Hitchcock Health

Davis Phinney Foundation

Dia de la Mujer Latina

Digestive Disease National Coalition

Dorney-Koppel Foundation, Inc.

Duke Health

Dystonia Advocacy Network

Dystonia Medical Research Foundation

Edwards Lifesciences Corporation

Epilepsy Association of North Carolina

Epilepsy Foundation

Families USA

Fannie Lou Hamer Cancer Foundation

FasterCures

Fight Colorectal Cancer

Friends of Cancer Research

GBS|CIDP Foundation International

Genetic Alliance

GLMA: Health Professionals Advancing LGBTQ Equality

Global Liver Institute

GO2 Foundation for Lung Cancer

Health Hats
Healthcare Leadership Council
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
LatinosAgainstAlzheimer'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
Nemours Children's Health System
NephCure Kidney International
Neuropathy Action Foundation
No Health Without Mental Health
North American Primary Care Research
Group
Northwestern University
NYU Langone Health
OCHIN
Ochsner Health System

Oncology Nursing Society
Parkinson's Foundation
Partnership to Improve Patient Care
Patient-Centered Primary Care Collaborative
Penn Medicine
Personalized Medicine Coalition
Phelan-McDermid Syndrome Foundation
Planetree International
Prisma Health
Project Sleep
Public Sector HealthCare Roundtable
Pulmonary Fibrosis Foundation
Pulmonary Hypertension Association
PXE International
Research!America
Restless Legs Syndrome Foundation
Scleroderma Foundation
Sleep Research Society
Society for Medical Decision Making
Society of General Internal Medicine
Society of Teachers of Family Medicine
Solve ME/CFS Initiative
Stanford School of Medicine
The Coalition for Disability Access in Health Science Education

The Coalition to Transform Advanced Care
The George Washington University LGBTQ+ Healthcare Community Advisory Board
The Larner College of Medicine
The Marfan Foundation
The Michael J. Fox Foundation for Parkinson's Research
The Myositis Association
The Society of Thoracic Surgeons
The Sturge-Weber Foundation
Tulane University Health Sciences Center
University of Colorado Anschutz Medical Campus
University of Florida
University of Hawaii John A. Burns School of Medicine
University of Kansas Medical Center
University of Maryland, Baltimore
University of Pittsburgh
University of Washington
U.S. COPD Coalition
U.S. Hereditary Angioedema Association
Vanderbilt University Medical Center
Virginia Commonwealth University
Wake Forest School of Medicine
Weill Cornell Medicine