



May 13, 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 undersigned are writing to express our strong support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI). Our health care system requires solutions that are both evidence-based and patient-centered, to improve care while also addressing health care spending. PCORI is uniquely set up to meet this challenge, as it is the only organization dedicated to funding comparative clinical effectiveness research (CER) studies comparing which treatment approaches work best, for which patients, given their needs and preferences. The goal is to help health care providers and payers better understand health care treatment options and to help patients and those who care for them make better informed health and health care decisions. Delivering care that is most clinically effective and incorporates outcomes that matter to patients is both cost effective and essential to our well-being as a nation.

As of December 2018, PCORI has awarded more than \$2.4 billion in grants to more than 600 research-related projects in 44 states across the U.S. In 2014, PCORI saw the first large number of research results from its funded studies reported in major medical journals. Several of these projects generated particularly promising evidence for improving care and patient outcomes in key areas, such as cardiovascular disease, prostate cancer, opioid prescribing, and type 2 diabetes management.

PCORI-funded research also supports personalized care by discouraging ineffective and low-value care. In fact, the U.S. Government Accountability Office concluded in its March 2018 report that PCORI is fulfilling its Congressional mandate to develop and promote the application of solid methodology standards for conducting trustworthy CER.

Unless Congress acts, however, all of this work will cease at the end of September 2019. To build on the momentum to date and to enable PCORI to continue its work toward achieving smarter and more efficient health care spending, we ask you to consider the following recommendations.

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

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. This is a vitally important function, and 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. 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 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-centered, 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.

Ensure PCORI stays true to its mission of patient-centered research by maintaining its mandate to conduct comparative clinical effectiveness research.

All stakeholders agree that high-quality, evidence-based care is crucial to reducing costs in the health care 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.

In creating PCORI, Congress committed to build the evidence base for improved health decisions, seeking to empower patients and drive innovation and value in health care. Reauthorization is an opportunity for Congress to ensure that PCORI continues to uphold this commitment and serve the needs of an evolving health care system.

We look forward to engaging with you throughout the reauthorization process. Thank you for your consideration of our recommendations.

Sincerely,

Organizations

AcademyHealth

Academy of Managed Care Pharmacy

AfricanAmericansAgainstAlzheimer's Network

Alliance for Aging Research

American Academy of Family Physicians

American Academy of Pediatrics

American Academy of Neurology

American Association for Dental Research

American Association for Respiratory Care

American Association for the Study of Liver Diseases

American Association of Colleges of Pharmacy

American Association of Neurological Surgeons and Congress of Neurological Surgeons

American Association of Orthopaedic Surgeons

American Association on Health and Disability

American Chiropractic Association
American College of Physicians
American College of Surgeons
America's Essential Hospitals
American Heart Association
American Liver Foundation
American Lung Association
American Medical Informatics Association
American Multiple Endocrine Neoplasia Support
American Parkinson Disease Association
American Psychological Association
American Society for Transplantation and Cellular Therapy
American Society of Hematology
American Society of Nephrology
American Thoracic Society
American Urological Association
Arthritis Foundation
Associated Medical Schools of New York
Association for Clinical and Translational Science
Association for Community Affiliated Plans
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
Better Medicare Alliance
Brain Injury Association of America
BrightFocus Foundation
Caregiver Action Network
Cedars-Sinai
Celiac Disease Foundation
Children's Hospital of Philadelphia
Cholangiocarcinoma Foundation
Cincinnati Children's Hospital Medical Center
Clinical Research Forum
Coalition for Clinical and Translational Science
Coalition for Disability Health Equity
Coalition to Transform Advanced Care (C-TAC)
Columbia University Irving Medical Center
COPD Foundation
Creighton University School of Medicine
Crohn's & Colitis Foundation
Cure HHT

Dartmouth Hitchcock Health
Davis Phinney Foundation
Digestive Disease National Coalition
Dorney-Koppel Foundation
Duke University School of Medicine
Dystonia Advocacy Network
Dystonia Medical Research Foundation
Epilepsy Association of North Carolina
Epilepsy Foundation
Families USA
FasterCures
Fight Colorectal Cancer
Friends of Cancer Research
GBS|CIDP Foundation International
Genetic Alliance
Global Healthy Living Foundation
Global Liver Institute
Go2Foundation for Lung Cancer
Harvard Medical School
Healthcare Leadership Council
Healthcare Research Associates LLC/ The S.T.A.R. Initiative
Heart Valve Voice US
Hydrocephalus Association
ICAN, International Cancer Advocacy Network
Indiana University
Infectious Diseases Society of America
International Foundation for Gastrointestinal Disorders
International Pemphigus and Pemphigoid Foundation
Interstitial Cystitis Association
Johns Hopkins University & Medicine
Lakeshore Foundation
LatinosAgainstAlzheimer's Network
Louisiana Public Health Institute
Lupus and Allied Diseases Association Inc.
Lymphatic Education & Research Network
Mended Hearts
Men's Health Network
METAvivor
Muslims for Evidence Based Healthcare
National Alliance on Mental Illness
National Alopecia Areata Foundation
National Ataxia Foundation
National Blood Clot Alliance
National Fibromyalgia and Chronic Pain Association
National Health Council
National Hispanic Medical Association
National Kidney Foundation
National Multiple Sclerosis Society

National Organization for Rare Disorders (NORD)
National Pancreas Foundation
National Partnership for Women & Families
National Psoriasis Foundation
NEC Society
Nemours Children's Health System
NephCure Kidney International
Neuropathy Action Foundation
NHMH - No Health without Mental Health
North American Primary Care Research Group
NYU School of Medicine
Ochsner Health System
Parkinson's Foundation
Partners Healthcare
Partnership to Improve Patient Care
Patient-Centered Primary Care Collaborative
Phelan-McDermid Syndrome Foundation
Planetree International
Powerful Patient Inc.
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 (SRS)
Society of General Internal Medicine
Society of Teachers of Family Medicine
Stanford University School of Medicine
Sterling Health IT
Sturge-Weber Foundation
The Marfan Foundaton
The Michael J. Fox Foundation for Parkinson's Research
The Robert Larner MD College of Medicine at The University of Vermont
The Society of Thoracic Surgeons
Tulane University School of Medicine
UC San Francisco (UCSF)
University Hospitals, Cleveland, Ohio
University of Alabama at Birmingham
University of California System
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 New Mexico Health Sciences Center
University of Pennsylvania Health System (Penn Medicine)
University of Pittsburgh
University of Virginia Health System
USCOPD Coalition
US Hereditary Angioedema Association
UW Medicine
Vanderbilt University Medical Center
Virginia Commonwealth University
Wake Forest School of Medicine
Washington University, St. Louis
Weill Cornell Medicine

PCORI Ambassadors

Bill Adams, PCORI Ambassador, Erhard, Minnesota
Peter Anderson, PCORI Ambassador, Charleston, West Virginia
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Kimerly Coshow, PhD, PCORI Ambassador, Parkinson's Disease Patient & Research Advocate, Blue Ridge, Georgia
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Heather Guidone, PCORI Ambassador, Atlanta, Georgia
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Philip Posner, PCORI Ambassador, Arlington, Virginia
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Freddie White-Johnson, President & CEO, Fannie Lou Hamer Cancer Foundation Director, Mississippi
Network for Cancer Control and Prevention
Ron Wincek, PCORI Ambassador, Atlanta, Georgia

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