



November 1, 2019

The Honorable Richard Neal
Chairman
House Committee on Ways and Means
1102 Longworth House Office Building
Washington, DC 20515

The Honorable Frank Pallone
Chairman
House Committee on Energy and Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Kevin Brady
Ranking Member
House Committee on Ways and Means
1139 Longworth House Office Building
Washington, DC 20515

The Honorable Greg Walden
Ranking Member
House Committee on Energy and Commerce
2322-A Rayburn House Office Building
Washington, DC 20515

Dear Chairmen Neal and Pallone and Ranking Members Brady and Walden,

The undersigned are writing to express our appreciation for the passage of legislation to reauthorize the Patient-Centered Outcomes Research Institute (PCORI) in your respective Committees and urge you to finalize a long-term reauthorization of PCORI, maintain its current funding sources, and continue its mandate to conduct comparative clinical effectiveness research (CER). 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's patient-centered mission and reauthorization.

While the PCOR Trust fund was extended through November 21st in the Continuing Resolution (H.R. 4378/ PL 116-59), it did not extend the funding mechanisms for PCORI to receive FY2020 funds during this short extension. Without this funding, PCORI will be unable to fund new research and its ongoing operations will be negatively impacted. Our priority is to ensure that long-term and consistent funding for PCORI be reauthorized. However, we also urge that if there is another short-term extension, PCORI's funding streams be continued as well.

As of June 2019, PCORI has awarded more than \$2.4 billion in grants and contracts to more than 700 research-related projects in 44 states across the U.S. 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.

PCORI's mission is to generate relevant, trustworthy evidence to help all Americans make informed healthcare decisions. In particular, addressing the healthcare needs of older Americans is one of PCORI's major areas of research. PCORI has funded 134 studies involving older adults more than 30 of which are specifically designed to help older adults and their caregivers make better-informed decisions about their healthcare options. PCORI-funded research is helping older adults stay in their homes longer and lead healthier, more resilient lives.

Enact a Long-Term reauthorization of PCORI that maintains its current funding mechanisms

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.

The ROI on Medicare's investment in PCORI is already very high. Much of PCORI's work focuses on older adults—with results that can help older adults achieve the outcomes they want, reduce the burden major health problems impose on them, and even lower their costs. PCORI-funded research also reinforces the Centers for Medicare and Medicaid Services' (CMS) efforts to advance an informed healthcare system that improves health care decision-making by patients and their providers. No other type of organization does the type of research PCORI does, and consistent, predictable funding is imperative to resource their work.

Maintain 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, and driven by a diverse multi-stakeholder Board of Governors and a patient-centered mission. 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.

We laud your leadership in taking action to achieve a long-term, fully-funded reauthorization of PCORI and look forward to engaging with you to finalize legislation to extend its patient-centered mission as soon as possible.

Sincerely,

Please contact Laura Hanen at laura.hanen@dbr.com if you would like to be removed from the letter or to be added if your organization is not listed below.

Organizations

Academy of Managed Care Pharmacy
AcademyHealth
AfricanAmericansAgainstAlzheimer's Network
Alliance for Aging Research
American Academy of Family Physicians
American Academy of Neurology
American Academy of Pediatrics
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
American Association of Nurse Practitioners
American Association of Orthopaedic Surgeons
American Association on Health and Disability
American Chiropractic Association
American College of Physicians
American College of Surgeons
American Congress of Rehabilitation Medicine
American Diabetes Association
American Heart Association
American Liver Foundation
American Lung Association
American Medical Informatics Association
American Multiple Endocrine Neoplasia Support
American Occupational Therapy Association
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
America's Essential Hospitals
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
Congress of Neurological Surgeons
COPD Foundation
Creaky Joints (Global Healthy Living Foundation)
Creighton University School of Medicine
Crohn's and 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
Fannie Lou Hamer Cancer Foundation
FasterCures
Fight Colorectal Cancer
FORCE: Facing Our Risk of Cancer Empowered
Friends of Cancer Research
GBS|CIDP Foundation International
Genetic Alliance
GLMA: Health Professionals Advancing LGBTQ Equality
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
Indiana University

Infectious Diseases Society of America
International Cancer Advocacy Network
International Foundation for Gastrointestinal Disorders
International Pemphigus and Pemphigoid Foundation
Interstitial Cystitis Association
Johns Hopkins University & Medicine
Lakeshore Foundation
LatinosAgainstAlzheimer's Network
Livpact
Louisiana Public Health Institute
Lupus and Allied Diseases Association Inc.
Lymphatic Education & Research Network
Mended Hearts
Men's Health Network
METAvivor
Mississippi Network for Cancer Control and Prevention, The University of Southern Mississippi
Moffitt Cancer Center
Muslims for Evidence Based Healthcare
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 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
Necrotizing Enterocolitis Society
Nemours Children's Health System
NephCure Kidney International
Neuropathy Action Foundation
New York University School of Medicine
No Health without Mental Health
North American Primary Care Research Group
OCHIN
Ochsner Health System
Oncology Nursing Society
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
Society of General Internal Medicine
Society of Teachers of Family Medicine
Stanford University School of Medicine
Sturge-Weber Foundation
The George Washington University Cancer Center
The Marfan Foundaton
The Michael J. Fox Foundation for Parkinson's Research
The Society of Thoracic Surgeons
Tulane University School of Medicine
University Hospitals, Cleveland, Ohio
University of Alabama at Birmingham
University of California, Los Angeles
University of California, San Francisco
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 Utah
University of Vermont Larner College of Medicine
University of Virginia Health System
University of Washington, UW Medicine
US COPD Coalition
US Hereditary Angioedema Association
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

Sonya Ballentine, PCORI Ambassador Chicago Health Disparities Center, Illinois
Rosie Bartel, Patient Advocate, Chilton, Wisconsin
James Beck, MD, Vice Dean for Government Affairs and Health Care Policy, Marshall University Joan C. Edwards School of Medicine, Huntington, West Virginia
Jennifer Canvasser, PCORI Ambassador, Davis, California
Martie Carnie, PCORI Ambassador, Senior Patient Experience Advisor, Center for Patients and Families, Brigham and Women's Hospital, Boston, Massachusetts
Thomas Carton, Chief Data Officer, Principal Investigator, Louisiana Public Health Institute
Matt Cheung, PCORI Ambassador, Los Gatos, California
Kimerly Coshow, PhD, PCORI Ambassador, Parkinson's Disease Patient & Research Advocate, Blue Ridge, Georgia
Amy Eisenstein, PCORI Ambassador, Chicago, Illinois
Maureen Fagan, PCORI Patient Experience Panelist and Chief Experience Officer, University of Miami Health System
Joel Gelfand,
Venus Gines, President & Founder, Dia de la Mujer Latina, Manvel, Texas
Lawrence Goldberg MD, PCORI Ambassador, Philadelphia, Pennsylvania
Regina Greer-Smith, PCORI Ambassador, Illinois
Heather Guidone, PCORI Ambassador, Atlanta, Georgia
James Harrison, PCORI Ambassador, Assistant Professor, University of California, San Francisco
Jill Harrison, Director of Research, Planetree International, Derby, Connecticut
Marcia Horn, PCORI Ambassador, Phoenix, Arizona
Matthew Hudson, Ph.D., M.P.H, Director of Cancer Care Delivery Research, Greenville, South Carolina
Wenora Johnson, PCORI Ambassador, Illinois
Leslie MacGregor Levine PhD, VMD, JD, PCORI Ambassador, advisory panel member and merit reviewer, patient advocate, Neuropathy Action Foundation, Boston, Massachusetts
Susan Lin, PCORI Ambassador, Advisory Panel member, and Merit Reviewer, Round Hill, Virginia
Donald A. McClain, Senior Associate Dean for Clinical Research Director, Clinical and Translational Science Institute, Wake Forest School of Medicine
Seth Morrison, PCORI Patient Reviewer and patient advocate, Las Vegas, Nevada
James Pantelas, PCORI Ambassador, Howell, Michigan
Maria Pellerano, PCORI Ambassador, New Brunswick, New Jersey
Philip Posner, PCORI Ambassador, Arlington, Virginia
Joan D. Powell, MDS Patient Advocate, Laguna Niguel, California
Ting Pun, PCORI Ambassador and Stanford Healthcare PFAC, Portola Valley, California
Bobbie Reed, PCORI Ambassador, Wexford, Pennsylvania
Anita Roach, M.S., PCORI Ambassador, Arlington, Virginia
Brendaly Rodriguez, MA, CPH, University of Miami Miller School of Medicine
Beverly Rogers, PCORI Ambassador, Indianapolis, Indiana
Carol Schulte, PCORI Ambassador, Red Bank, New Jersey
Norah Schwartz, Ph.D., PCORI Ambassador, San Diego, California
Sandra Sufian, Associate Professor; University of Illinois, College of Medicine and Applied Health Science
Jeff Taylor, PCORI Ambassador, Palm Springs, California
Rachelle Tepel PhD, PCORI Ambassador, Arlington, Virginia
Beverly Watkins, PCORI Ambassador, New York, New York
David White, PCORI Ambassador and Chair, Advisory Committee on Patient Engagement, Prince George's County, Maryland

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: Speaker Nancy Pelosi
Minority Leader Kevin McCarthy