

November 1, 2019

The Honorable Richard Neal

Chairman

House Committee on Ways and Means

1102 Longworth 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 Frank Pallone Chairman

House Committee on Energy and Commerce

2125 Rayburn 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 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**](mailto: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 Diabetes Association

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

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

FasterCures

Fight Colorectal Cancer

Friends of Cancer Research

GBS|CIDP Foundation International

Genetic Alliance

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

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

New York University School of Medicine

No Health without Mental Health

North American Primary Care Research Group

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 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 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 Vermont Larner College of Medicine

University of Virginia Health System

University of Washington 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

Maureen Fagan, PCORI Patient Experience Panelist and Chief Experience Officer, University of Miami Health System

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