



November 4, 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 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 184 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,

#### **Organizations**

Academy of Managed Care Pharmacy  
AcademyHealth  
AfricanAmericansAgainstAlzheimer's Network  
Alliance for Aging Research  
Alpha-1 Foundation  
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  
March of Dimes  
Mended Hearts  
Men's Health Network  
METAvivor  
Mississippi Network for Cancer Control and Prevention, The University of Southern Mississippi  
Moffitt Cancer Center  
Muscular Dystrophy Association (MDA)  
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 Patient Advocate Foundation  
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  
Nontuberculous Mycobacteria Info & Research  
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  
Personalized Medicine Coalition  
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  
Solve ME/CFS Initiative  
Stanford University School of Medicine  
Sturge-Weber Foundation  
The George Washington University Cancer Center  
The Marfan Foundaton  
The Society of Thoracic Surgeons  
The University of North Carolina at Chapel Hill  
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 Iowa Health Care  
University of Kansas Medical Center  
University of Maryland, Baltimore  
University of Miami Health System  
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  
US COPD 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  
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  
Lyn Behnke, PCORI Ambassador, Assistant Professor of Nursing, University of Michigan - Flint  
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  
Catherine P. Hanson, Director Patient Engagement and Patient and Family Centered Care, University of Miami Health System  
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  
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Anita Roach, M.S., PCORI Ambassador, Arlington, Virginia  
Brendaly Rodríguez, MA, CPH, Patient, PCORI Ambassador and member PCORI Advisory Committee on Patient Engagement, 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  
MaryAnne Sterling, PCORI Ambassador, Virginia  
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

Florence Thicklin, PCORI Ambassador, PCORI Merit Reviewer, and Patient Engagement/Advocate, Illinois  
Beverly Watkins, PCORI Ambassador, New York, New York  
Destiny Watkins, PCORI Ambassador  
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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: The Honorable Lamar Alexander  
The Honorable Patty Murray  
The Honorable Mark Warner  
The Honorable Bill Cassidy  
The Honorable Chris Van Hollen  
The Honorable Shelley Moore Capito