



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  
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  
Brendaly Rodriguez, MA, CPH, University of Miami Miller School of Medicine  
Anita Roach, M.S., PCORI Ambassador, Arlington, Virginia  
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: The Honorable Bill Cassidy  
The Honorable Mark Warner  
The Honorable Shelley Moore Capito  
The Honorable Chris Van Hollen



May 13, 2019

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

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

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

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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  
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Indiana University  
Infectious Diseases Society of America  
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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)  
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Washington University, St. Louis  
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