Dear Senators Warner, Cassidy, Van Hollen, and Capito,

On behalf of the Friends of PCORI Reauthorization, we are writing to express our appreciation for your continued support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI).

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 reauthorization. In particular we laud you for including in your discussion draft of the “Patient Centered Outcomes Research Institute Reauthorization Act of 2019” a 10-year reauthorization, maintenance of the current funding mechanisms, and continuation of the mandate to conduct comparative clinical effectiveness research (CER). As you consider additional policy changes, we also hope that you will give priority consideration to the comments that will be provided by individual stakeholders engaged in Friends of PCORI Reauthorization given their strong interest in maintaining PCORI’s patient-centered mission and diverse stakeholder input.

Support for a ten-year reauthorization of PCORI and its current funding mechanism 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.

**Support for maintaining 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. 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.

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. This outcome is driven currently by giving diverse stakeholders a voice and a vote on the Board of Governors, including patients.

We have advised our members that it is vitally important to also provide comments to you on the additional policy changes that are proposed in the discussion draft, particularly on their potential implications for advancing PCORI’s patient-centered mission and diverse stakeholder input. We appreciate your leadership to achieve a long-term, fully-funded reauthorization of PCORI and look forward to working with you throughout the legislative process to ensure PCORI remains patient-centered.

Sincerely,

The Honorable Tony Coelho
Chairman
Partnership to Improve Patient Care

The Honorable J. Phillip Gingrey, MD
Senior Advisor
District Policy Group

Enclosure

cc: The Honorable Chuck Grassley
The Honorable Ron Wyden
National Organizations
(183 Members)

AcademyHealth
Access to Integrative Medicine Health Institute
Alliance for Aging Research
American Academy of Family Physicians
American Academy of Neurology
American Academy of Sleep Medicine
American Academy of Pediatrics
American Association for Cancer 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 Nurse Practitioners
American Association on Health and Disability
American Chiropractic Association
American College of Physicians
American College of Surgeons
American Diabetes Association
American Gastroenterological Association
American Heart Association
American Liver Foundation
American Medical Information Association
American Multiple Endocrine Neoplasia Support
American Occupational Therapy Association
American Parkinson Disease 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 | Council of Academic Family Medicine |
| Association of Pathology Chairs | CreakyJoints (Global Healthy Living Foundation) |
| Association of Public and Land-grant Universities | Creighton University School of Medicine |
| Association of Rehabilitation Nurses | Crohn's & Colitis Foundation |
| Association of Schools and Programs of Public Health | Cure HHT |
| Association of University Centers on Disabilities | Dartmouth Hitchcock Health |
| Asthma and Allergy Foundation of America | Davis Phinney Foundation |
| Autism Speaks | Dia de la Mujer Latina |
| Better Medicare Alliance | Digestive Disease National Coalition |
| Bobby Jones Chiari & Syringomyelia Foundation | Duke Health |
| Brain Injury Association of America | Dystonia Advocacy Network |
| BrightFocus | Dystonia Medical Research Foundation |
| Cancer Support Community | Edwards Lifesciences Corporation |
| Cedars-Sinai | Epilepsy Association of North Carolina |
| Celiac Disease Foundation | Epilepsy Foundation |
| Center for Endometriosis Care | Families USA |
| Cholangiocarcinoma Foundation | Fannie Lou Hamer Cancer Foundation |
| Cincinnati Children's Hospital | FasterCures |
| Clinical Research Forum | Fight Colorectal Cancer |
| Coalition for Clinical and Translational Science | Friends of Cancer Research |
| COPD Foundation | GBS|CIDP Foundation International |
| Genetic Alliance | GLMA: Health Professionals Advancing LGBTQ Equality |
| Global Liver Institute | GO2 Foundation for Lung Cancer |
Health Hats
Healthcare Leadership Council
Healthcare Research Associates
Heart Valve Voice US
Hydrocephalus Association
Infectious Diseases Society of America
International Cancer Advocacy Network
International Foundation for Gastrointestinal Disorders
International Pemphigus and Pemphigoid Foundation
Interstitial Cystitis Association
Janssen Pharmaceuticals
Johns Hopkins University and Medicine
Lakeshore Foundation
Latinos Against Alzheimer’s
Livpact
Louisiana Public Health Institute
Lung Cancer Alliance
Lupus and Allied Diseases Association Inc.
Lymphatic Education & Research Network
March of Dimes
Mended Hearts
Men’s Health Network
Merck
Moffitt Cancer Center
Muscular Dystrophy Association
Muslms for Evidence Based Healthcare
My Epilepsy Story (MES)
National Alliance of Healthcare Purchaser Coalitions
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 Hispanic Medical Association
National Kidney Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Pancreas Foundation
National Partnership for Women & Families
National Psoriasis Foundation
NEC Society
Nemours Children’s Health System
NephCure Kidney International
Neuropathy Action Foundation
No Health Without Mental Health
North American Primary Care Research Group
Northwestern University
NYU Langone Health
OCHIN
Ochsner Health System
Oncology Nursing Society  The Coalition to Transform Advanced Care
Parkinson's Foundation  The George Washington University LGBTQ+ Healthcare Community Advisory Board
Partnership to Improve Patient Care  The Larner College of Medicine
Patient-Centered Primary Care Collaborative  The Marfan Foundation
Penn Medicine  The Michael J. Fox Foundation for Parkinson's Research
Personalized Medicine Coalition  The Myositis Association
Phelan-McDermid Syndrome Foundation  The Society of Thoracic Surgeons
Planetree International  The Sturge-Weber Foundation
Prisma Health  Tulane University Health Sciences Center
Project Sleep  University of Colorado Anschutz Medical Campus
Public Sector HealthCare Roundtable  University of Florida
Pulmonary Fibrosis Foundation  University of Hawaii John A. Burns School of Medicine
Pulmonary Hypertension Association  University of Kansas Medical Center
PXE International  University of Maryland, Baltimore
Research!America  University of Pittsburgh
Restless Legs Syndrome Foundation  University of Washington
Scleroderma Foundation  U.S. COPD Coalition
Sleep Research Society  U.S. Hereditary Angioedema Association
Society for Medical Decision Making  Vanderbilt University Medical Center
Society of General Internal Medicine  Virginia Commonwealth University
Society of Teachers of Family Medicine  Wake Forest School of Medicine
Solve ME/CFS Initiative  Weill Cornell Medicine
Stanford School of Medicine
The Coalition for Disability Access in Health Science Education