

Dear Members of Congress:

As you work to enact legislation that will transform and shape the American health care system to be more patient-centered, we, as patients, people with disabilities, caregivers, providers, researchers, policy professionals, employers, and insurers, are **writing to express our strong support for the continued authorization of the Patient-Centered Outcomes Research Institute (PCORI) and urge you to protect its funding for the coming years.** We believe that PCORI's mission of conducting patient-centered outcomes research (PCOR) is critical to your goal of establishing a health system where patients and providers are empowered to make informed healthcare decisions.

PCORI was established in 2010 to fund and build the nation's capacity to conduct comparative clinical effectiveness research (CER). Recognizing the need to empower patients, providers, and other stakeholders to make informed healthcare decisions, PCORI established a unique process to meet and engage people where they are - allowing real people – patients, caregivers, and clinicians -- to drive PCORI's research focus, transforming discussion about how novel science can support medical innovation and answer questions important to patients and other stakeholders. Delivering care that is most clinically effective for each individual patient – based on outcomes that matter to patients – is cost effective and yields health and quality-of-life improvements essential to our productivity and well-being as a nation.

PCORI is doing the vital comparative studies that assess the real-world impact of targeted therapies, and the systems that deliver those therapies. PCORI's work will support patients and providers in determining which targeted therapies to choose and how to deliver that therapy most effectively. PCORI-funded research supports decisions made by a patient with their physician and findings support personalized (or precision) medicine by not only getting people the right care at the right time, but by preventing people from getting ineffective and worthless care. In fact, the GAO concluded in its March 2015 [report](#) that PCORI is fulfilling its Congressional mandate to generate evidence patients and those who care for them can use to make better-informed health care decisions. To date, PCORI has invested nearly \$1.6 billion in more than 570 patient-centered CER studies and related projects that support CER. These studies are in process, and results are not yet in. However, there are some early findings. For example, a study looking at the best ways to treat children with osteomyelitis, a serious bone infection, found that using oral antibiotics was just as effective as standard of care--treatment via a PICC line--but resulted in less complications and dramatically improved quality of life for the children and their families.

We support PCORI's mission to do research differently. For all the advances it produces, traditional research does not always address the questions patients and people with disabilities face daily about which approach works best in their particular situations. PCORI is the only organization dedicated to funding studies, driven by patient and stakeholder input, comparing which approaches work best, for whom, and under what circumstances. PCORI has spent a great deal of time and resources to build the infrastructure to conduct research in such a patient-focused and patient-involved way. Not only has this effort paid dividends by ensuring their research is meaningful to patients and providers who are making healthcare decisions, but they have completely changed the paradigm of other types of research. Patient engagement in drug

and device development has been a strong focus of the Food and Drug Administration, and Congress has also recognized its importance by including provisions in the 21st Century Cures Act to further the science around patient engagement. We all have PCORI to thank for being a pioneering leader.

Additionally, PCORI has built an infrastructure to support the nation's capacity to conduct clinical research. The National Patient-Centered Clinical Research Network (PCORnet) is a large national network for conducting CER with integral involvement of patient organizations and large clinical networks, making it highly representative of a diverse population of patients and people who seek better health. PCORnet will advance the nation's capacity to conduct clinical research faster, more efficiently, and at lower cost. This resource will not only help generate the evidence needed to make informed healthcare decisions, but can also help spur innovation and advance cures.

As Congress seeks to make changes to our nation's public and private health care programs, we look forward to working with you to ensure that PCORI's research is effectively translated to support an evolving and patient-centered system of care. If we hope to align our health system with our considerable investment in personalized and precision medicine, PCORI must be sustained.

PCORI's work has just begun. It will accelerate learning and it needs more time so its true impact can be felt. If given this time, these early successes can be built upon, and improve the nations' health.