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June 25, 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

RE: Reauthorize the Patient-Centered Outcomes Research Institute (PCORI)

Dear Chairman Neal and Ranking Member Brady:

As Congress works to transform and shape the American health care system to be more patient-centered, I am writing to express Genetic Alliance's strong support for the reauthorization of the Patient-Centered Outcomes Research Institute (PCORI). PCORI's mission of conducting patient-centered outcomes research 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). To date, PCORI has invested nearly \$2.4 billion in more than 600 patient-centered CER studies and related projects that support CER. The research funded by PCORI can support a value-based health care system by informing the development and use of tools such as decision aids as well as the health system infrastructure that empowers patients and providers to determine what therapies are right for each individual patient. PCORI-funded research also supports personalized care by discouraging ineffective and low-value care. In fact, the GAO concluded in its March 2018 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.

Genetic Alliance supports 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. Additionally, PCORI has partnered with patients and clinical networks to build an infrastructure to support the nation's capacity to conduct CER called the National Patient-Centered Clinical Research Network (PCORnet), a large national network for conducting CER faster, more efficiently, and at lower cost. As part of

the Coordinating Center for PCORnet, Genetic Alliance has been able to advocate for and promote systems for community-informed research and speedy, appropriate dissemination.

We support reauthorization because of PCORI's commitment to funding research that matters most to individuals, families, and communities. Genetic Alliance's values and solutions are based in a long and deep history working in and with people affected by rare and common diseases and conditions. We believe the participation and leadership of diverse stakeholders in research is imperative for elevating voices; leveraging stories; identifying the most impactful research questions; informing successful participation and retention; generating insight for value assessment, quality product development, and effective project execution; and—ultimately—ensuring that knowledge makes its way back to people for better care.

If we hope to align our health system with our considerable investment in personalized and precision medicine, PCORI must be sustained. Please contact me at sterry@geneticalliance.org should you have questions or seek further information.

Sincerely,

A handwritten signature in black ink, appearing to read 'Sharon F. Terry', with a stylized, cursive script.

Sharon F. Terry
President & CEO