

Cerebral Palsy Foundation Awarded Funding for Patient-Centered Research Among Adults with Cerebral Palsy

Funding from the Patient-Centered Outcomes Research Institute (PCORI) will support Comparative Clinical Effectiveness Research

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Ashley Harris Whaley

Foundation (CPF) has been awarded funding through the Eugene Washington PCORI Engagement Award Program, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). The funds will support a project titled Supporting Engagement in Patient-Centered Comparative Clinical Effectiveness Research (CER) Among Adults with Cerebral Palsy.

Although cerebral palsy is the most common lifelong physical [disability](#) in the world, affecting more than an estimated 50 million people worldwide and nearly 1 million in the United States, adults with Cerebral Palsy remain

profoundly overlooked in healthcare and research. Studies show adults with CP are twice as likely to develop chronic conditions such as heart disease, stroke, and diabetes, and yet they face major gaps in access to coordinated care and tailored health guidance. Less than 5% of CP research funding to date has focused on adults, leaving a critical void in evidence to guide treatment, services, and policy.

Ashley Harris Whaley, Director of Adult Programs for the [Cerebral Palsy Foundation](#), is leading this engagement project - bringing together adults with cerebral palsy, caregivers, clinicians, and researchers to create resources and a research agenda that reflect the priorities and lived experiences of the cerebral palsy community.

The project will:

- Develop a comprehensive curriculum that addresses health literacy, research literacy, CER principles and methodologies, engagement and advocacy strategies, and effective communication.
- Assemble a steering committee of patients, caregivers, and experts to guide curriculum

development, training, and dissemination.

- Recruit members to join a new stakeholder group that will collaborate to identify research priorities that are directly meaningful to adults with cerebral palsy.

- Disseminate the curriculum through virtual trainings, a digital knowledge-sharing platform, and a culminating virtual event in 2027.

"Adults with cerebral palsy remain one of the most underserved and underrepresented populations in healthcare research," said Ashley Harris Whaley. "This project creates an opportunity to build knowledge, confidence, and leadership among adults with CP, while ensuring that their voices shape the future of patient-centered research."

"The Cerebral Palsy Foundation has long been dedicated to advancing research and care that reflects the real needs of the CP community. We are honored to receive this support from PCORI to launch a project that empowers adults with CP to be true partners in shaping research agendas." added Rachel Byrne, Executive Director of the Cerebral Palsy Foundation.

This project is part of a portfolio of projects funded by PCORI to help develop a community of patients, caregivers, clinicians and other stakeholders who are better equipped to engage as partners in all phases of patient-centered comparative clinical effectiveness research (CER) and to disseminate results of PCORI-funded studies. Through its Engagement Award Program, PCORI is fostering a broad network of individuals, communities and organizations whose lived experiences and unique perspectives help shape research that is more patient-centered, relevant and useful.

PCORI is a nonprofit organization with a mission to fund research that empowers patients, caregivers and the broader healthcare community with evidence-based information needed to support informed health care decisions.

About CPF

The Cerebral Palsy Foundation is a leading, global nonprofit foundation dedicated to enhancing the lives of millions of people worldwide living with cerebral palsy and their families. We focus on cutting-edge research, transforming healthcare systems, improving prevention and early detection, and providing effective interventions across the lifespan— while accelerating efforts to find a cure. We are changing the future for cerebral palsy.

Learn more about our work at cerebralpalsyfoundation.org

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