NATIONAL APHASIA ASSOCIATION

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PRESS RELEASE

<u>National Aphasia Association</u> has been awarded funding for a project to establish and disseminate a clear set of research priorities based on the experiences and needs of people living with aphasia. The project also seeks to strengthen the organization's research capacity and build a strong, informed, engaged community that is ready to take part in research that truly reflects their lived experiences.

We are pleased to announce the National Aphasia Association (NAA) has been approved for a funding award through the <u>Eugene Washington PCORI Engagement Award Program</u>, an initiative of the Patient-Centered Outcomes Research Institute (PCORI). The funds will support the establishment of a clear set of research priorities on the impacts of aphasia as identified by those living with aphasia. It will also help the NAA develop more research capacity.

Maura Silverman, MS, CCC-SLP, Executive Director will lead the engagement project at the National Aphasia Association. The project will bring together people with aphasia, family members, healthcare providers and researchers to shape future research and advocacy. This effort will identify the biggest challenges and core impacts that people with aphasia face and help guide future research that focuses on what matters most to them. The goal is to make sure that people with aphasia and their families are included in every part of the research process—from deciding what issues are most important to influencing future research and care. Once the priorities are set, the NAA will create a roadmap to guide future research and programs. Finally, the results of the project will be shared widely through the NAA's website, newsletters, and presentations to reach as many people as possible. By working together, the NAA wants to ensure research reflects real-life experiences and improves care for people with aphasia.

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Project Lead Maura Silverman is thrilled that "This opportunity made possible by PCORI is a powerful affirmation of the National Aphasia Association's renewed commitment to ensuring that the voices of people with aphasia are front and center in research that affects their lives. We are proud to lead this effort, as the established national leader in patient-centered support, advocacy, education, and support of research for people living with aphasia and their care partners."

Dr. Jackie Hinckley, Chair of the NAA's Board of Directors, said: "The project is unique in that it ensures that the impacts of living with aphasia, and the lived experience of people with aphasia and their families, will be in a form that can be used to drive critical research to improve lives."

The project titled "Building capacity for patient-centered CER (clinical effectiveness research) in stroke-related aphasia" 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 creating an expansive network of individuals, communities and organizations who can leverage their lived experience and expertise to influence research to be more patient-centered, relevant and useful.

PCORI is a nonprofit organization with a mission to fund research that will provide patients, their caregivers, and clinicians with the evidence-based information that is needed to make better-informed health care decisions.

https://aphasia.org/core-impact/

