

## Saturday

### **Stakeholder perspectives: National Aphasia Association primary progressive aphasia advisory board and survey results**

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#### **State of the Art**

Primary Progressive Aphasia (PPA) has received increasing research attention and public awareness, but stakeholder input from people living with PPA and their families is needed to guide research and clinical initiatives. Stakeholder-engaged research for people living with stroke-induced aphasia has been established, with projects such as Project BRIDGE (<https://www.projectbridge.online/>) systematically involving stakeholders in decision-making. There are, however, few initiatives that directly involve input from people living with PPA.

#### **Methodology**

The National Aphasia Association (NAA) has formed a PPA task force composed of researchers, clinicians, and an advisory board of people with PPA and their loved ones. The task force will collaboratively address the needs of families coping with PPA. At an initial advisory board meeting, objectives were identified during a structured, aphasia-friendly discussion. A follow-up survey was completed by members of the NAA PPA Listserv.

#### **Results**

The survey currently has 59 responses from throughout the United States and seven additional countries. Communication partners (62%), persons with PPA (30%), and dyads (7%) ranked the advisory board's objectives in order of priority: 1) PPA support groups and email helpline; 2) Locating accurate information about PPA; 3) Finding knowledgeable SLPs; 4) Resources; 5) Awareness/Advocacy; and 6) Connections and fundraising. Additional survey data will be compiled regarding the experiences of stakeholders with physicians, in receiving a diagnosis, and in receiving speech-language therapy.

#### **Conclusion**

Perspectives from PPA stakeholders gathered by the NAA PPA task force will inform future research and clinical initiatives.

#### **Conflicts of interest**

Rebecca Khayum:

Financial Disclosures:

- Owner of therapy company, MemoryCare Corporation (2010-present)
- Owner of digital health services company (2020-present)

Non-financial Disclosures:

- Board Member, Aphasia Access, 2022-present
- Co-chair, National Aphasia Association PPA Task Force, 2021-present