Rebecca: We have our distinguished panelists here and ready. Dr. Brice is going to moderate this panel for us, and we will have a question and answer period after.

Dr. Brice: I’d like to introduce Audrey Holland.

Audrey Holland, Ph.D., Regents’ Professor Emeriti, University of Arizona: Hi, I am delighted to be here and excited about the conference. I am going to talk briefly about cooperative research in aphasia.

It is important to figure out what we do not want to do anymore.
I want to begin by thanking persons with aphasia, and their loved ones for making what we know about aphasia and its treatment, its causes, its prevention, its neurotomy as of this date, a reality.

Of course, persons with aphasia and their families have also contributed to what we used to think, but now know is incorrect or incomplete. THIS IS ALMOST EQUALLY IMPORTANT to the field, but pretty painful to this of you who have helped in studies that fail.

You have contributed hours spent in letting researchers scan your brains for science.

You have spent hours in taking tests, and participating in treatment studies that may or may not have benefitted you (or the rest of the aphasia community).

You have spent hours you might have rather spent on the golf course in training our students.
So where would people like me be were it not for generous, curious, motivated people like you?

This marks my 50th year in doing aphasia treatment, teaching & research

I have learned many things, almost all of them from People with Aphasia and their families (and my students)

I have learned that aphasic people and their families are amazing, generous, caring, & involved!

I have learned a lot about what TO DO,

I have learned a raft of things about what NOT TO DO
My time here is short, so positives, not negatives.

So let’s begin with the **YOUR** willingness to contribute to clinical studies that might or might not help **YOU**

But also to things that will help **others** with aphasia

HERE ARE SOME EXAMPLES

**Dr. Holland:** You have contributed to the most recent advances to the treatment of aphasia.

PWA and families have provided data to validate many new approaches to aphasia treatment in the past 20 years.

These include 2 of my own

Communicative Coaching
SCRIPT Training

But on a larger stage

Semantic Feature Analysis (SFA)
Verb Network Strengthening Treatment (VNeST)
Treatment of Underlying Forms (TUF)
Semantic Complexity Training
AphasiaBank is another example.

Funded by NIH in 2007

AphasiaBank currently has produced data or methodology for almost 500 research papers and publications.

That has happened because

Almost 300 English-speaking PWA, as well as a substantial number of French, Spanish, German, Cantonese and Mandarin-speaking people with aphasia have contributed their language to AphasiaBank.
Similarly, ONE PROGRAM…. C-STAR (Center for the Study of Aphasia Recovery University of South Carolina, Columbia, SC) has amassed over 400 state-of-the-art neuroimages volunteered by people with aphasia.

For researchers who focus on the relationship of brain damage and aphasia & its effects on treatment.

The most interesting recent (hot off the press) is a collaboration between clinicians, researchers, PWA and families, is the VERSE study (2018) from Australia (Godecky, et al).

VERSE is a randomized control trial that indicates that more therapy in the early phases (first 12 weeks post stroke) does not improve outcomes over traditional speech therapy in that time period.

This study does NOT mean that therapy is ineffective, but it does suggest that modest involvement early on is okay… and suggesting that more therapy later, as probably most of you know, is what is needed!
Has anyone in this room been aphasic for 20 years?

Well, I have only talked in very general ways about your research contributions from roughly 1997

But People with aphasia have contributed to what we know since 1861

Leborgne (TanTan)
Pierre Paul Broca

So a very heartfelt THANK YOU to the carers and persons with aphasia who have made my and other researchers’ careers possible.
Dr. Holland: Let’s fix that jagged stool. There are things that NIH will not funding. I am glad PCORI can help.

The aphasia research stool is rather “tippy”
It is skewed toward...

What neuroscience can learn from aphasia about how damaged brains as well as how healthy brains process language

What medical science can learn from aphasia about minimizing the damage caused by stroke or TBI, or preventing such conditions altogether

Generally, federal funding sources are tipped toward healthcare advances in the biological sciences, rather than pragmatic clinical studies, such as those embraced by PCORI
So here is the shout out for PCORI for funding meetings such as this one!!!

My hopes for this meeting

That we develop a workable template or two that crafts new legs for our three legged stool, putting the needs of PWA and families for clinical research on a par with those of researchers and funders

That we find ways for families and PWA to have voices in determining the art and science of aphasia rehabilitation

That we forge new alliances, make new friends, learn from each other and leave this meeting filled with energy for this important task
I will close with two examples of research that should be of interest to families and people with aphasia, but are probably outside the scope of NIH, but inside the interests of PCORI.

One is my belief that developing resilience & optimism in families and people with aphasia is as important as effecting communication growth & probably will enhance it!

The other is a straightforward clinical study, demonstrating the value of helping aphasic people to train their pet dogs to follow commands, learn tricks, etc., in improving quality of life in their aphasic owners.

This the fascinating approach of Sharon Antonucci, of Moss Rehabilitation Center.

So that is really all I have to say, except to thank Jackie and Alejandro for asking me to participate.

I think this is a ground breaking meeting and I am so happy to be a part of it!

Applause.