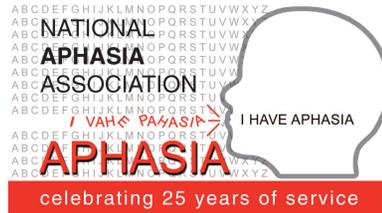




Northwestern University Feinberg School of Medicine

Cognitive Neurology and  
Alzheimer's Disease Center



The Association for  
Frontotemporal Degeneration  
Opening the gateway to help and a cure

# The Dr. Lawrence Albert Memorial Webinar Series on PPA

Organized by

**Cognitive Neurology and Alzheimer's Disease Center (CNADC)**

**The National Aphasia Association (NAA)**

**The Association for Frontotemporal Degeneration (AFTD)**

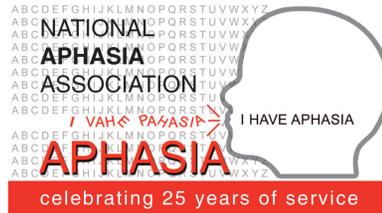
Forming the

***Speech Language Pathologist (SLP) Primary Progressive Aphasia (PPA)  
Education Coalition***



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## Dr. Lawrence Albert

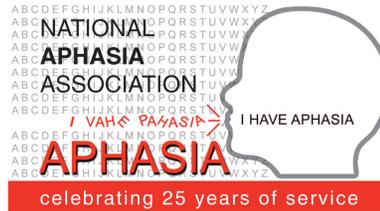


***This webinar series is possible because of a generous sponsorship by Kathi and Peter Arnow, the family of Larry Albert, who battled PPA until 2011.***



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## Webinar 2:

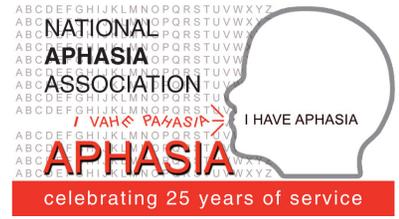
# Treatment for persons with PPA: An Adaptable Communication Support Approach



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Professor of Neurology, Pediatrics, Biomedical  
Engineering, and Otolaryngology at the  
Oregon Health & Science University



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Assistant Professor in the  
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San Francisco State University



## Disclosure:

**Melanie Fried-Oken, Ph.D., CCC-SLP**

**No relevant financial OR non-financial relationships to disclose**

**Maya Henry, Ph.D., CCC-SLP**

**No relevant financial OR non-financial relationships to disclose**

## CEUs

**Only attendees of the live webinar on June 27 are eligible for CEUs. The three CEU forms must be fully completed and submitted as directed by 5 pm Eastern on July 1. The webinar is offered at .15 CEUs for Intermediate Level; Professional. Access to the archived recording of the webinar will be made available for informational purposes, but not for CEUs.**



The Long Island Speech-Language-Hearing Association is approved by the Continuing Education Board of the American Speech-Language-Hearing Association (ASHA) to provide continuing education activities in speech-language pathology and audiology. See course information for number of ASHA CEUs, instructional level and content area. ASHA CE Provider approval does not imply endorsement of course content, specific products or clinical procedures.

# Treatment for persons with PPA: A communication supports approach

**Melanie Fried-Oken, Ph.D., CCC/Sp**  
**OHSU**  
**Portland, OR**

**Maya Henry, Ph.D., CCC/SP**  
**UCSF**  
**San Francisco, CA**



# Goals for this afternoon

- 1) To present 3 phases of speech-language treatment for individuals with PPA.
- 2) To describe restorative, compensatory and environmental strategies within a communication support framework.
- 3) To propose measurable treatment goals for individuals with PPA.

# PRINCIPLES OF TREATMENT

# Understand the progressive nature of speech-language impairments

- Unlike stroke, in PPA, speech-language abilities gradually decline
- Initially, communication difficulties are the only cause of limitation to ADLs
- Ultimately, concomitant cognitive and motor difficulties develop

# Address the symptoms (differ for each variant)

- Nonfluent/agrammatic variant
  - Syntax and motor speech (AOS)
- Semantic variant
  - Naming and single-word comprehension (semantics)
- Logopenic variant
  - Naming and repetition (phonology)

## Consider the goal: Functional communication

- Maximize communication at each stage of illness
- Consider the individuals in the context of their environment
- Tailor treatment approach with current status; take into account likely progression

# Communication Supports

## Unaided Approaches (Natural modes)

- Speech
- Vocalization
- Gestures
- Eye gaze
- Body language
- Sign language
- Partner co-construction

## Aided Approaches (Low tech and high tech tools)

- Paper and pencil
- Communication books
- Communication boards and cards
- Speaking computers
- Talking typewriters
- Speech generating devices
- Mobile technologies

# Ideal model: Staged treatment approach

- **Assess** → **Treat** → **Assess** → **Treat**
- Goals evolve with symptom progression
- **3 stages**
  - I. Restorative
  - II. Shift toward aided approaches
  - III. Environmental support and partner training

# Group treatment throughout the continuum

- Psychosocial benefits
- Supported communication practice
- Group problem-solving

# Non-linguistic considerations that may affect treatment outcomes

- **Changes in cognition**
  - Memory
  - Executive functions
  - Visuospatial processing
- **Changes in behavior**
  - Social and emotional changes
  - Disinhibition, apathy
- **Motor changes**
  - Weakness, incoordination
  - Limb apraxia

# COMMUNICATION APPROACHES



# PHASE I: RESTORATIVE

# Restitutive treatment for speech and language impairments in PPA

- Background
  - Despite considerable recent progress understanding the neurobiology of PPA, very little research effort directed at behavioral rehabilitation
  - Pessimism on the part of clinical professionals and third party reimbursers
  - Case reports and single-subject experimental research provide descriptions of behavioral intervention attempts in <30 individuals with PPA

## Restitutive treatment for speech and language impairments in PPA

- A number of treatment approaches appear promising (e.g., Henry et al., 2008; Beeson et al., 2011; Newhart et al., 2009)
- **Treatment effects can be substantial and lasting**
- Can result in changes in speech-language behaviors and observable changes in neural processing (fMRI)

# Restitutive PPA treatment by variant

- Vast majority of studies address lexical retrieval, but sentence production and written language also treated (for review, see Henry et al., 2010)
- **Most research to-date with semantic variant (sv)**
  - significantly improved naming for trained items, with maintenance up to six 6 months post-treatment in some cases (Henry et al., 2008a; Jokel et al., 2002/2006; Heredia et al., 2009; Mayberry et al., 2011; Snowden & Neary, 2002; Graham et al., 1999)
- Several nonfluent/agrammatic (nfv) cases have shown significant improvement for trained items (e.g., Jokel et al., 2009)
- **Only a few logopenic (lv) cases in the treatment literature** (Beeson et al., 2011; Henry et al., 2008b; Henry et al., in press; Newhart et al., 2009)

# Treatment for naming in logopenic and semantic variants (Henry et al., in press)

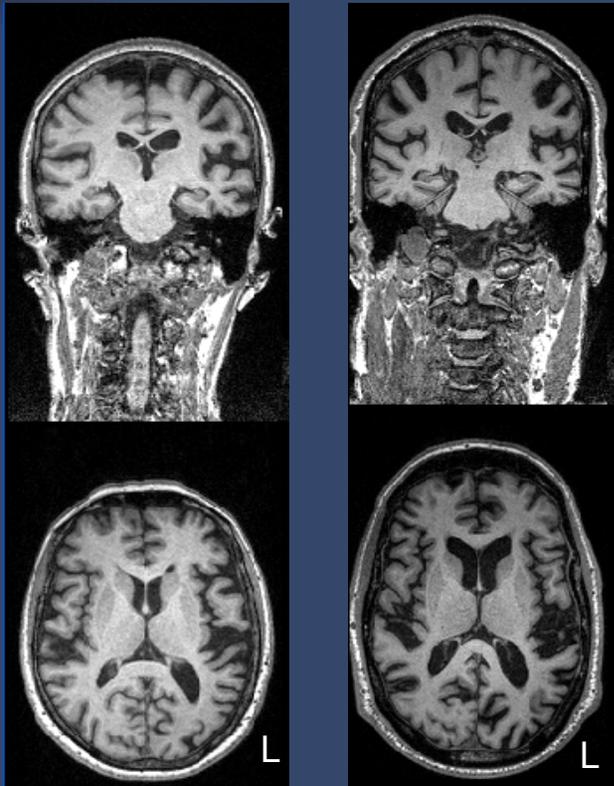
- Anomia is a common feature
  - Different underlying cause
- Training hierarchy designed to capitalize on spared cognitive-linguistic processes and encourage self-cueing
- Treatment
  - One hour session per week until 80% criterion met on each set
  - Daily homework
    - Copy and Recall Treatment (Beeson & Egnor, 2006)

# Participants

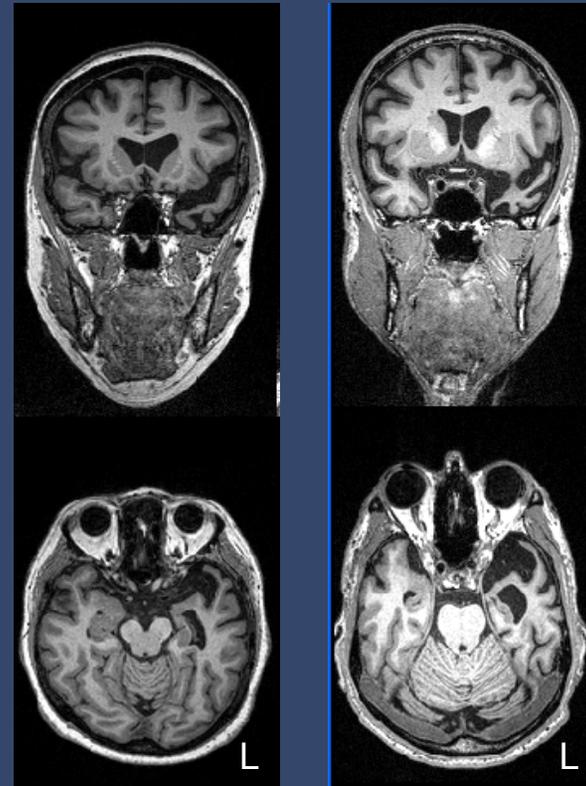
- **lvPPA cases (5)**
  - relatively fluent spoken language
  - word-finding pauses
  - occasional phonemic paraphasias
  - spared object knowledge, motor speech, syntax
- **svPPA cases (5)**
  - fluent speech
  - marked anomia
  - single-word comprehension deficits
  - impaired object knowledge
  - spared syntax, motor speech

# MRI findings

Logopenic variant



Semantic variant



# Naming treatment in logopenic and semantic variants

LV



guided semantic feature analysis



if not named, 1<sup>st</sup> letter and sound elicited



if not named, written model provided,  
spoken prod. elicited



repetition x3



semantic plausibility judgments x5



recall 2 semantic features + name

SV



generate **two known features**  
(may be autobiographical)



if not named, **four written choices provided**



correct choice and spoken model provided (if needed)



repetition x3

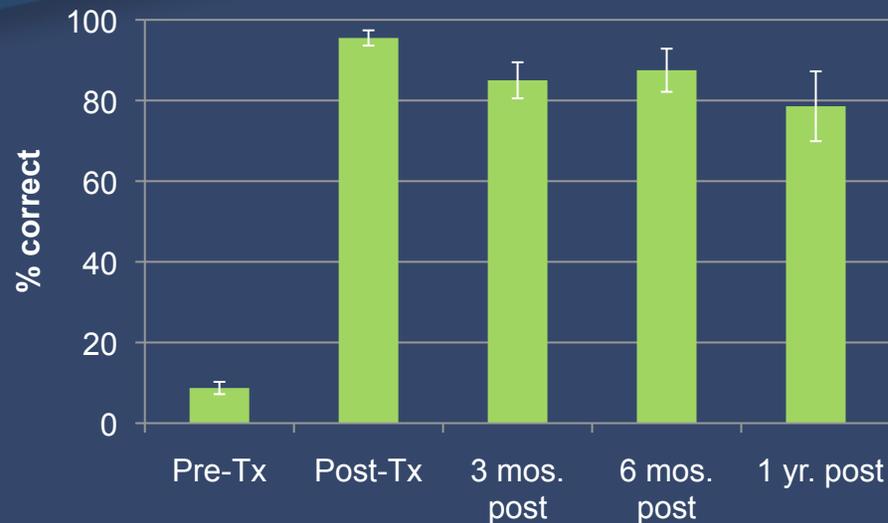


semantic plausibility judgments x5



recall 2 semantic features + name

# Treatment results in lv and svPPA



- Robust acquisition and maintenance of trained items
- Modest generalization to untrained items and tasks
- Reports of improved word-finding (spoken and written) in everyday communication

In PPA, stability = progress

# Benefits of treatment *in their own words*

- Video 1
- Video 2

# Restitutive naming treatment

- Appropriate in mild-moderate stages
  - Can evolve over time
- Capitalizes on spared cognitive-linguistic functions
  - Differ by variant
- Encourage *self*-cueing
  - Will aid in generalization and maintenance of gains

## Phase II: A shift toward aided approaches

- Expressive language is less efficient
- Verbal participation in all activities decreases
- Telephone use decreases or is avoided
- Conversations become imbalanced

# Consider communication demands

## – Different setting

- Employment
- Homes
- Groups
- Community events



## – Different partners

## – Topics

- Familiar vs. unfamiliar



## – Modes of communication

- Telephone
- Face to face, spontaneous
- Written
- Electronic



# Functional assessment tools

- Social Networks Inventory (Attainment Company)
- Aphasia Needs Assessment (Garrett & Beukelman, 2006) <http://aac.unl.edu>
- CETI: Communicative Effectiveness Index (Lomas et al., 1989)

# Social Networks

## Client's Circles:

1. Intimate partners (family)
2. Good friends
3. Acquaintances
4. Employees
5. Strangers

**SUMMARY SHEET B – CCP AND MODES**

DATE \_\_\_\_\_ TYPE OF COMMUNICATOR \_\_\_\_\_

**# OF PARTNERS/PRIMARY MODE**

3

**# OF PARTNERS/PRIMARY MODE**

4

**# OF PARTNERS/PRIMARY MODE**

1

**# OF PARTNERS/PRIMARY MODE**

2

**# OF PARTNERS/PRIMARY MODE**

5

**# OF PARTNERS/PRIMARY MODE**

5

**ALL MODES RELIED ON:**

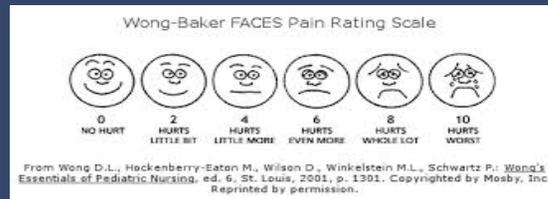
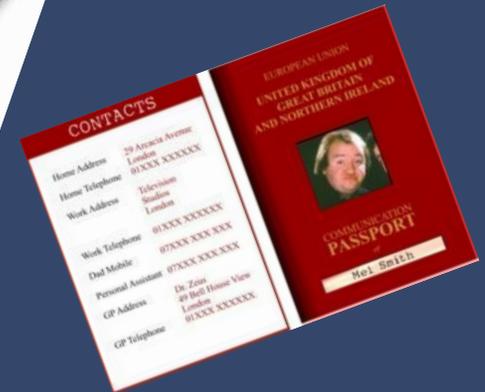
- facial expressions/body language
- gestures
- vocalizations
- manual signs
- speech
- writing/drawing
- nonelectronic communication board/book
- electronic communication device
- special communication software used on a computer
- phone
- email
- other \_\_\_\_\_

**MODES CURRENTLY USED THAT ARE:**

EFFECTIVE/EFFICIENT	NOT EFFECTIVE/NOT EFFICIENT
1 _____	1 _____
2 _____	2 _____
3 _____	3 _____
4 _____	4 _____
5 _____	5 _____

# Low tech options

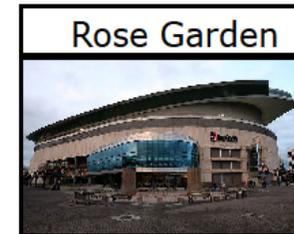
- Communication books
- Communication passports
- Photo albums
- Pictures
- Newspapers
- Communication boards
- Cards
- Remnants
- Written choice and continuum lines
- Paper and pencil



## The Treatment Challenge:

*To put the patient's residual lexicon **visually in front of him** so that the patient can access needed vocabulary to participate in daily activities as language skills decline.*

# Conversational board: My sports teams



# Functional activities board

Weeding



Firewood



Beach House



Ocean View



Casper



Stair Repair



Clamming



Fireplace



Stern Wheeler



Boulder City



Walmart



Costco



Laughlin



London Bridge



Fred Meyer



Thriftway



# Low tech AAC study

(Fried-Oken & Rowland, submitted)

## Method

- **20 individuals with PPA**
- 10 neurotypical adults and 20 individuals with AD
- **Personalized communication boards**
- Trained in board use with RA and with spouse
- **Scripted and natural conversations; 6 *with* and 6 *without* AAC**

## PPA Results

- Targeted words produced at initial prompt significantly greater with AAC
- **Number of questions posed by RA or spouses to elicit target words significantly reduced with AAC**

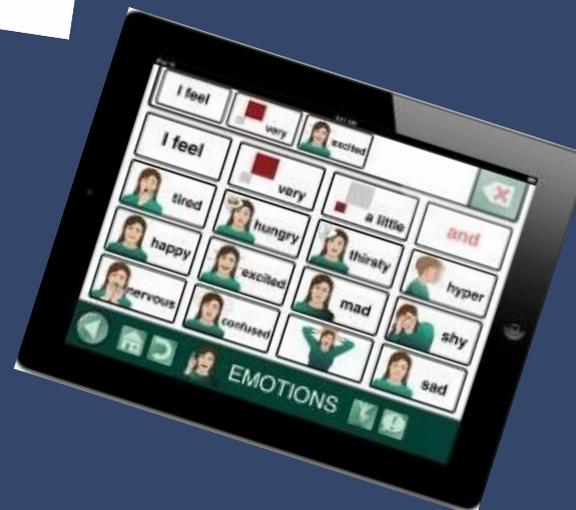
# Interpretation of results



- Low tech AAC provides meaningful lexical support during structured conversations for people with PPA.
- Low tech AAC significantly reduces lexical scaffolding provided by the conversation partner.
- This approach should be part of a PPA treatment protocol.

# High tech options

- Dedicated speech generating devices
- Mobile technology devices



## Device features to consider

- Digitized vs. synthesized speech output
- Speech output intensity (location of speakers and dB levels)
- Visual complexity of screen
- Working memory demands of device
- Amount of learning required (ease of use)
- Size and portability
- Insurance reimbursement
- Technical support

# User features to consider

- Previous experience with technology
- Support for training
- Partner's experience with technology
- Working memory abilities
- Vision and hearing abilities
- Cognitive strategies and skills
- Motivation
  - “I bought this for mom to use.”
  - “She can't seem to find the correct page.”

# Current mobile technology for PPA study: Sharing new information with/without AAC

## Method

- *Justification: “ I can understand what he is saying when I start the conversation. But when Jim comes up to me and wants to tell me something, and I don’t know the topic, I have no idea what he is talking about!”*
- 4 adults with PPA (2 mild; 2 severe)
- Completed 3 activities with RA
- RAs populated 5 different layouts in GoTalk Now app with photos & speech
- Barrier task: Tell your spouse what you did this afternoon
- 3 conversations with no AAC support;  
3 conversations with AAC

## Results

- Significantly greater report of gist with AAC than with no app
- For subjects with severe PPA: Total words spoken with AAC increased significantly compared to speech only condition;
- Specific app layout did not affect language performance

# Visual Scene in GoTalk Now app



- 3 videos:** (1) speech + gestures  
(2) speech + gestures + writing  
(3) speech + gestures + writing + GoTalk Now app

# Rules of the road



***KISS: Keep it  
simple and  
supportive***

# Rules of the road



***Assistive  
Technology  
without  
training is  
not  
assistive!***

## Phase III: Aided approaches and emphasis on environmental modifications

- Engineering the environment
- Communication partner training

# Examples of natural environmental supports

- Pointing to weather pictures in newspaper to indicate time of day
- Pointing to framed boards on the family picture wall *at eye level*
- Using mail received from the bank to indicate questions about finances
- Flipping through photos in address book during a family visit
- Visiting a museum: Using photos to discuss what the home town looked like

# Partner training

- “Should I finish his sentences? Give him the words?”
- **Support all forms of communication**
- Count to 10 in your head before expecting a response
- **Speak in a quiet environment, establish eye contact and reduce distractions**
- Set up a way to “come back to that later.”

# Communication modes reported by 13 subjects with AD and PPA at 6 mo. generalization probes

- Address book (2/13)
- Ads
- Calendar (2/13)
- Children's bible stories
- **Comm. Board (8/13)**
- **Comm. photo booklet (5/13)**
- Computer
- Cookbook
- Costumes
- Electronic photo frame
- E-mail
- Entertainment program
- Flashcards
- Gestures/ sign language/ pantomime (3/13)
- Letters
- Magazine (2/13)
- Mail
- Maps (2/13)
- Museum
- Newsletters
- **Newspaper (5/13)**
- Numbers
- Paper & pen/writing (3/13)
- **Photos & photo albums (8/13)**
- Post it notes
- Resident/staff directory
- Scrap book
- Show Me
- Singing
- Skype

# [www.reknewprojects.org](http://www.reknewprojects.org) -> Primary Progressive Aphasia -> Communication supports



REKNEW Projects  
Child Development and Rehabilitation Center

## Guidelines for Communicating with People who have Communication Difficulties

### Remain Calm and Positive

- Smile and remain interested even when conversation strays.
- Keep a level head, a calm voice, remain as relaxed as possible.
- Focus on what the person *can* do, not what they can't do.
- Look for opportunities to support interaction.

### Keep it Simple

- Speak in short, concrete sentences.
- Rephrase to keep topic focused when person is confused.
- Respond immediately to communication attempts.
- Provide clear choices between no more than two possibilities.

### Be Polite

- Make sure the person is willing to have a conversation.
- Maintain eye contact (if culturally appropriate).
- Reassure and support the person if stuck or frustrated.
- Thank the person for having a conversation.

### Support All Forms of Communication

- Encourage and validate the use of *any* communication techniques.
- Use pictures or other aids to help with word finding difficulties.
- Encourage pointing and other gestures.
- Encourage facial expressions.
- Encourage writing and drawing.

### Reduce Frustration

- Request more information on a topic if unclear.
- Avoid quizzing just to get the "right" answer.
- Do not directly contradict the person even if they are wrong.
- Draw focus away from frustrating or embarrassing problems.

### Be Aware and Informed

- Monitor changing needs for communication support.
- Practice using all communication strategies yourself.
- Role play with friends, family and therapists to understand how to handle communication breakdowns.

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FAX: 503-494-2859 • email: [bakerg@ohsu.edu](mailto:bakerg@ohsu.edu)  
Web: <http://www.ohsu.edu/oidd/reknew/index.cfm>



# [www.reknewprojects.org](http://www.reknewprojects.org) -> Primary Progressive Aphasia -> Communication supports

## Helpful Hints for Conversation

Use the examples below to help you think about how to begin a conversation, keep a conversation going, redirect the conversation, or to expand the conversation beyond one topic.

### Request Details

- Can you give me a specific example?
- How did that happen?
- Why did you go?
- What were the names of the other people?

### Request More Information to Expand the Conversation

- Is there anything else you can think of?
- Tell me more about...
- Had you done similar things?

### Ask About Context

- Who else was there?
- What were you wearing?
- What color was it?
- Who did you travel with?
- What did you eat?
- How did the flowers smell?
- Had you ever been there before?

### Ask About Time/Sequence

- When did it happen?
- What day of the week was it?
- Was it dark or light?
- What time of year did it happen?
- How long did it last?
- What happened next?

### Ask About Place

- Where did it happen?
- Were you inside or outside?
- What room were you in?
- Where were you sitting?
- What sorts of things were around you?
- Did you stay there or go somewhere else?

### Acknowledge Any Response

- Yeah, I like it there too.
- You're right, she is a wonderful friend.
- I remember doing that, and then we...
- That was a long time ago, but what I'm really asking is...
- I'd love to talk more about that.

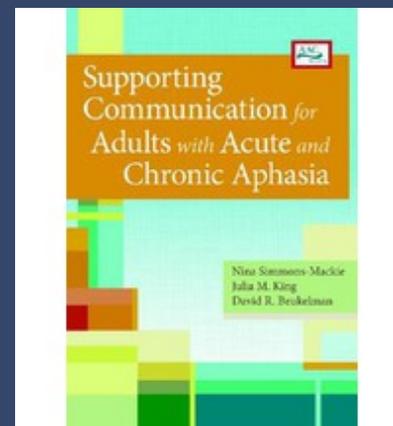
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# Documenting successful outcomes for people with PPA

- Stability = progress
- Comprehension and production in any modality are acceptable
- Writing measurable treatment goals for progressive impairments of speech and language

# *Book and website references for AAC*

- [www.aac-merc.com](http://www.aac-merc.com): Research to practice AAC for PPA webinar (AAC Rehabilitation Engineering Research Center)
- Simmons-Mackie, King & Beukelman (2013)
- Brookes Publishing



**[www.aac-rerc.com](http://www.aac-rerc.com)  
and  
[www.reknewprojects.org](http://www.reknewprojects.org)**

***MFO*-Portions of the work in this presentation have been funded in part by the National Institute on Disability and Rehabilitation Research (NIDRR), U.S. Department of Education under Grants #H133E030018 and #H133G080162**



**<http://memory.ucsf.edu>**

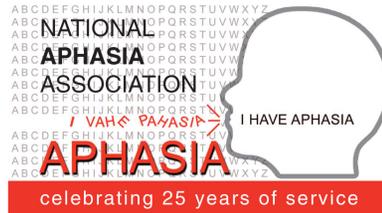
***MH*-Portions of the work in this presentation have been funded by the NIH (NIDCD F31DC010945; F32DC010945, NIAP01 AG019724, and NINDS R01NS050915)**





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## Q&A Session



**Melanie  
Fried-Oken  
Ph.D., CCC/Sp**



**Maya L.  
Henry,  
PhD, CCC-SLP**



**Ellayne  
Ganzfried  
MS, CCC-SLP**



**Darby  
Morhardt  
MSW, LCSW**

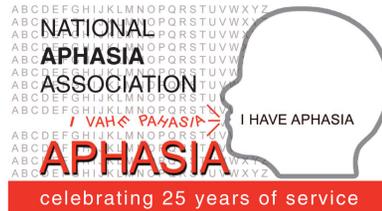


**Christina  
Wieneke**



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## For More Information on PPA

[www.brain.northwestern.edu](http://www.brain.northwestern.edu)

[www.aphasia.org](http://www.aphasia.org)

[www.theaftd.org](http://www.theaftd.org)

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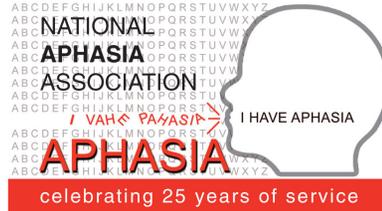
Maya Henry

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celebrating 25 years of service



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## PPA Helplines

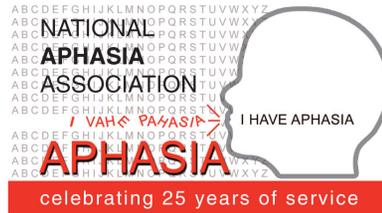
**AFTD (866) 507-7222**  
**info@theaftd.org**

**NAA (800) 922-4622**  
**responsecenter@aphasia.org**



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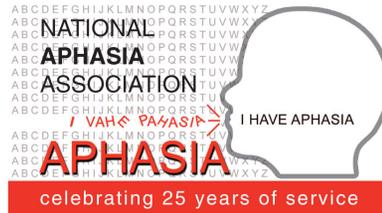
## CEUs

**Please submit the three CEU forms,  
as directed in your confirmation emails,  
by 5 pm Eastern, July 1.**



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**Our 3<sup>rd</sup> webinar will be on  
August 1 at 1 pm Eastern**

***Thank you and have a great day!***