

Aphasia Insights!

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“There is one thing stronger than all the armies in the world, and that is an idea whose time has come.”

Victor Marie Hugo (January 30, 1826-May 22, 1885) was a poet, novelist and campaigner for social causes. His most famous works include *Les Miserable* and *The Hunchback of Notre-Dame*.

Stroke Educator, Inc. is committed to educating the wider public about stroke and the 50 state “*Aim High for Aphasia!*” Aphasia Awareness Campaign.

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National Aphasia Awareness Campaign: *Aim High for Aphasia!*

By Tom Broussard, Ph.D.

My plan started with the *Aphasia in North America*

white paper (Nina Simmons-Mackie, Ph.D., 2018). The report describes the first gap summary as:

“Insufficient awareness and knowledge of aphasia by health care providers and the wider public.”

Aphasia affects about two million Americans and is more common than Parkinson’s Disease, cerebral palsy or muscular dystrophy (National Aphasia Association).

About 25%-40% of people with a stroke acquire aphasia and nearly 180,000 Americans develop the disorder each year. A recent survey by the National Aphasia Association (2016) reported that only 8.8% of respondents knew that aphasia is a language disorder and identified as “aphasia aware”.

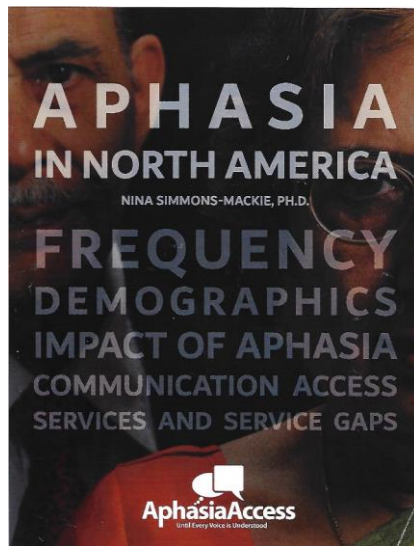
My contribution to the “call to action” is my plan, *Aim High for Aphasia!* It is the tagline for my National Aphasia Awareness Campaign after my stroke and aphasia in 2011 when I

lost my language and could not read, write or speak well. That is the definition of aphasia.

I am often referred to as *Johnny Appleseed of*

Aphasia Awareness and started my company, Stroke Educator, Inc. in 2015. It is dedicated to a national, 50-state Aphasia Awareness campaign. I have spoken at 24 states so far.

The plan continued with the publication of the *Stroke Diary* series; *Stroke Diary, A Primer for Aphasia Therapy* (2015); *Stroke Diary, The Secret of Aphasia Recovery* (2016) and *Stroke Diary, Just So Stories, How Aphasia Got Its Language Back* (2018).

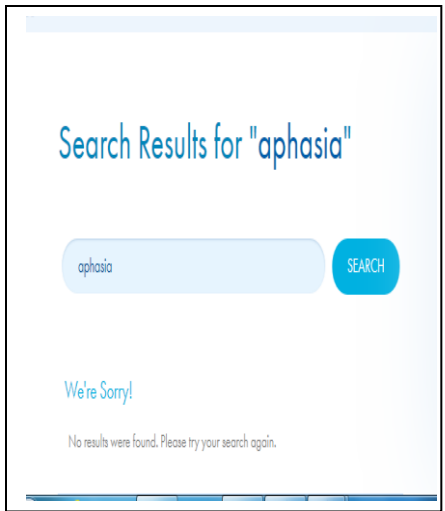


The next step includes the disseminating of aphasia information to local, state and national medical, hospital and healthcare professionals through print, video and film (PSA) specifically from the perspective of a person with aphasia (PWA). Hearing from a doctor or a therapist about aphasia is the first and vital step towards recovery. Hearing from stroke survivors (née stroke educators) who live with and recover from aphasia, can be transformative.

I have been speaking to thousands of people at various hospitals about aphasia and discovered that many hospitals do not provide *any* information about aphasia on their website. Everyone knows something about stroke but few know much about aphasia. I didn't know anything myself about aphasia until after *my* stroke. I started investigating why so many people, especially in the hospital and healthcare community, acknowledge so little about aphasia.

It turned out that most hospital staff (other than the speech-language therapists)

typically won't refer to a patient who has language problems as an aphasic or a person with aphasia (PWA). They might discuss that the patient is having problems with their language, can't find a word, or can't express what they want to say. But in my experience, the staff don't use the word "aphasia" as part of their day-to-day lexicon.



I presented *Aphasia, a national disorder that no one has ever heard of: A Study in Public Awareness of Aphasia at 20 Hospitals in Florida* at the 2019 Aphasia Access Leadership Summit in Baltimore, MD. Recently updated, 20 of the now 23 hospitals do not provide *any* online information about aphasia on their website. Their search engines answered with (or similar

words), "We're Sorry! No results were found."

We must provide information and training about aphasia and recovery to the wider healthcare community. The hospital community can be a huge part of helping the public learn more about stroke *and* aphasia, a national disorder that no one has ever heard of.

Join the cause...and check your local hospital's website for aphasia! The time has come!

Signed:

The Johnny Appleseed of Aphasia Awareness.