

Aphasia Insights!

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“That is the promise to glade, *the hill we climb if only we dare*. It’s because being American is more than a pride we inherit. It’s the past we step into and how we repair it. We’ve seen a forest that would shatter our nation rather than share it.”

The Hill We Climb
National Youth Poet
Laureate Amanda Gorman
January 20, 2021

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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Aphasia Recovery and *The Hill We Climb ... Together.*

(Inspired by the National Youth Poet Laureate, Amanda Gorman).

By Tom Broussard, Ph.D.

After my stroke and aphasia (loss of language), and as I got better, I started to describe my experience of having fallen off a cliff and climbing back up to describe what I had seen “down there.” My ability to describe the damage grew with each step upward.

While I was still unable to express my thoughts regarding my language deficits, I drew many pictures in my diary including one of several mountains with the word “aphasia” spread across the peaks of the range. I had a sense of “falling” as I looked at my “aphasia mountain” and could “see” letters falling down the slope.

But I could see that some letters (and words) didn’t fall all the way down. In some of my pictures, you can see that they stopped short.

While I could tell that some of those words didn’t make any sense there were other words that weren’t quite as “crooked”.

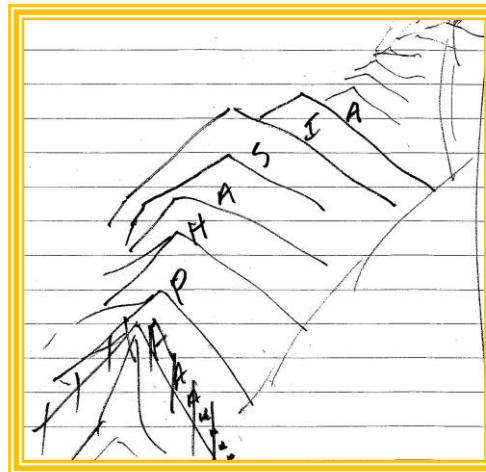
The deficits of aphasia are explained in various ways. My therapist, from her perspective, would explain my deficits through her written weekly reports. In my case, when I still couldn’t express what I had seen (or what my

therapist had told me), I used pictures in my diary to express what I was thinking without the words to describe it.

It wasn’t until later when I could “find” the words to help describe what I

was thinking (and drawing) back when those words had been lost. The pursuit of those lost words was the start of the climb, and it hasn’t stopped since.

Last month, I watched President Biden’s inauguration and listened to the new National Youth Poet Laureate, Amanda Gorman. She is an amazing young poet and provided the right tone for the administration’s approach. She faced many of her own hills to



Aphasia Mountain, Diary entry
11/17/2011

climb including having a speech impediment that resolved with a speech-language pathologist. It wasn't until I heard the words "the hill we climb" when I realized that people with aphasia (PWA) have their *own* hill that we all have to climb, as Gorman said, "if only we dare."

Ms. Gorman's challenge is my own ongoing ascent with *Aim High for Aphasia!* It is the tagline for my national Aphasia Awareness Campaign since the start of Stroke Educator, Inc. in 2015.

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 (2020) reported that only 7.0% of respondents knew that aphasia is a language disorder and identified as "aphasia aware".

My work includes 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) plus my fourth book, *The ABCs of Aphasia: A Stroke Primer* (2020).

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 step towards recovery. But hearing from stroke survivors who live with and recover from aphasia can be transformative.

I have been speaking to thousands of people 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 and 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. I did more research since then and now there are 20 of 23 hospitals that do not provide *any* 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 public.

The ABCs of Aphasia: A Stroke Primer is another step in the right direction and I have been donating copies of *The ABCs of Aphasia* to many hospitals in an effort to enlist them with the mutual hill of aphasia awareness that we have to climb *together*.

Signed: *The Johnny Appleseed of Aphasia Awareness; Author, Advocate, Activist*