



Mid-Atlantic Aphasia Conference Newsletter

www.midatlanticaphasiaconference.org

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From The Editor's Desk:

Happy New Year and Welcome!

This newsletter connects the **Mid-Atlantic Aphasia Conference** staff with the aphasia community through the written word. As editor, I am excited to share a variety of stories, articles, and resources to inform, inspire, and connect our community.

Aphasia is a communication disorder that is mostly caused by stroke or other brain injuries. This first session of the newsletter shares information about another condition that can cause aphasia: **Moya Moya**.

Whatever the cause, aphasia can have a huge impact on a person's ability to express themselves and understand language.

Despite the challenge, we join the aphasia community in declaring that aphasia does not define a person's worth or limit their potential for growth and connection.

Subscribe to the MAAC newsletter so you are sure to get every episode!

SCAN THIS QR CODE:



Future issues will focus on:

- raising awareness
- advocating for accessible communication
- the vital role of family, friends, and caregivers

We will also share success stories that showcase the resilience of individuals living with aphasia.

Denise Mendez

Get The Word Out! Aphasia!

The MAAC President, Mark Harder.

I was a plasterer for over 35 years and an apprentice plasterer instructor for 16 years. I had a new position as an international training coordinator. Seven months in, I had a heart attack and a stroke, leaving me with aphasia, low vision, and chronic pain. I couldn't read or write, could only say a few words, and had problems processing spoken words.

I tried to understand my pain, my low vision, the loss of my career and my language. My doctor asked me what my pain felt like. At that time, I could only say "good" or "bad" to indicate how it felt. Then at the next appointment I was able to say that it felt like "sunburn", - and metaphors began poetry!

I wrote my first poem on February 1, 2020, two years after my stroke. In September that same year, I created *Poems In Speech* on Zoom and then the next month, October 2020, I worked with *Virtual Connections* to be a co-host of *Speaking Poetry*. I published an Apple E-Book, *Poems in Speech Book June 22*, contributed poems in *Virtual Connections - Speaking Poetry Aphasia Art & Poetry* and Capital Health Aphasia Support Group *Aphasia Book: Stories, Poems, and Paintings*. I am a proud member of the Thursday Night Poets and was published with three poems in the chapbook, *Poetry is Chocolate*. I have contributed to *A Metabolic Cure For Sadness* - poems by *The Run My Mouth Collective*.

After the events of the National Aphasia Awareness Celebration of June 2020, I contacted Jim Burd and Dr. Denise Mendez to form the Mid-Atlantic Aphasia Conference. The next month, we were joined by Jenn Derry who matched our passion for aphasia advocacy. That momentum soared like wings as Dorothy Laven, Kevin Derry, and Crystal Laughlin broadened our horizons!

Moya Moya and Aphasia

My name is Crystal Laughlin, and I am the newest member of MAAC. Aphasia "moved in" on December 5, 2022. I was on vacation in the Dominican Republic - I woke up and I could not speak. That's when I was diagnosed with Moya Moya.

Moya Moya is a genetic disease where the arteries at the base of the brain narrow. The blood flow is limited and can cause a stroke. The left side of my brain was injured and that's how I acquired aphasia.

I am married and have a "bonus" son who is 26. I am one of 5 sisters and 11 nieces and nephews. I have a big family and am so happy to have joined MAAC.

Before my diagnosis I had never heard of aphasia or Moya Moya, and I think it is important to raise awareness. Awareness can save lives. My cousin was on that trip with me and she saved my life. She knew that aphasia was a sign of stroke and made sure I got medical attention!

The APHASIA BILL OF RIGHTS

As a person with aphasia you have the right to:

1. Be told that you have aphasia-and given an explanation of the meaning of aphasia
2. *Get the diagnosis of aphasia in writing*
3. Be told about resources, including local, regional, and national organizations
4. *Receive therapy with a qualified Speech-Language Pathologist*
5. Give informed consent for research



Aphasia Advocacy is Important!

WHY?

- *Increases aphasia awareness – gets the word OUT THERE!*
- **May improve overall quality of life of persons with aphasia.**
- *Improves social interaction and reduces isolation of persons with aphasia.*
- **It can increase and improve aphasia services.**
- *Increases support for continued Aphasia research.*
- **Empowers persons with Aphasia and their family and caregivers.**

<https://www.iraphasiatherapy.com/>

An Aneurysm, Aphasia, and other issues!

Jim Burd's Story- Part 1

I live in Hopewell Township. I've lived here virtually all my life. During that time I had two neurosurgeries. The first was when I was 16 years old and was the co captain of the wrestling team of Hopewell Valley Central High School. In **mid-December of 1968**, I was helping the gym teacher teach the fellows how to wrestle and suddenly I had, what I thought was a migraine headache. I went to the nurse who had my mother take me to our local doctor who treated me for the pain and I went to bed and I do not remember anything from that day until **March of 1969!**

A surgeon at University of Penn Hospital told my father that I had an **aneurysm** in my brain (one wall of a blood vessel weakened over years and then finally burst). I also had a blood clot in the brain too. The doctor said that if I had survived the surgery, I would probably have *complete paralysis*, if not that, because of the problem on the left side of the brain, I would have *paralysis on the right side of my body*.

After five hours of surgery I was sent to intensive care. I weighed 157 pounds and was in great shape. I was told that I woke up, pulled out the needles in my arm and started walking to the bathroom. I just pushed away the female nurses, who called two male nurses to grab me, placed me in bed and shackled me! I was told to call nurses if I had any needs at all. I was told that I did not eat, and when I was given a new liquid protein, when I was able to walk again- I weighed about 100 pounds. Also, I got pneumonia, and had a tracheotomy so I could breathe. But that wasn't the last issue... at that time, donated blood was not evaluated totally, so because of the transfusion I received hepatitis C.

In **late January 1969**, I was released from the hospital but had to go back to see the neurosurgeon every two weeks. At that time I had no memory of what had happened to me and I really could not speak or really understand what was being said to me. I knew all of my high school classmates, and I took my yearbook, covered the names and tried to put the proper name with each face. I had assistance from my parents and other family members and friends as I tried to speak and listen again. Then in **March 1969**, one day I woke up and could remember everything from that day on and the time before the day I was injured in December 1968, but I have no recall as I was recovering. I had assistance from a teacher and went back to high school and in 1970 I graduated.

Years went on, I went to Moravian College in Bethlehem, PA and graduated in 1974. In July 1979 I married Debbie, and in 1983 we had our son Matthew. I was in sales and my wife, who was in banking, became the owner of the Nursery Lane Kennel.

Part 2 will continue Jim's story...

Including **a fall from a roof** and **a second brain injury**, errors of prescribed medicine, and rehab work to improve his communication skills! **Be sure to see the next part of Jim's story in the next MAAC newsletter!**



Tie is one of the well-loved fur-babies who enrich the lives of the MAAC members.

Everyday Aphasia Advocacy!

Are you a person with aphasia? Did you know that you can be AN EVERYDAY APHASIA ADVOCATE?

As an advocate you can educate yourself and others about aphasia.

There are many ways to do this -we hope ONE of these ways will allow you to join us as EVERYDAY APHASIA ADVOCATES!

Get the **WORD** out! **APHASIA!**

- **Say it** –with friends, family, at the doctors’ offices, stores, etc.
- **Write it-** emails, blogs, written letters and cards!
- **Wear it-**order a t-shirt, bracelets, hats, mugs, and other aphasia SWAG
- **Show it-** magnets on the car and refrigerator, lawn flags, painted rocks
- **Repeat it** -Use the word, share the word, remember it!

The CareGiver’s Corner

Communication Hints: from the PWA (person with aphasia) to the Caregiver

A – Ask simple, direct questions

P -Provide more than one option to communicate (draw, write, point, etc.)

H – Help me to communicate if you are asked

A – Acknowledge when I (or you) are frustrated

S – Speak slowly and clearly

I – If you don’t understand, don’t fake it...say so!

A – Allow time for me to respond

Reference: The Aphasia Caregiver Guide
-2020 National Aphasia Association

Questions from Tie!

Tie has a question.

“What is Aphasia?”

“And if you drank from my water bowl, will I get it?”

Great questions Tie.

First, aphasia affected my speech. It is hard for me to say words but it also affects

my writing and reading. That’s why I read so much and so slowly!

Yes, Tie-you are right! I write poems to express myself and say them out loud.

Aphasia affects how I understand spoken words too.

I am not deaf, but I may ask people to repeat themselves to give myself time to process what they have said.

I have aphasia because I had a stroke, but other people might have aphasia because of a brain injury, a tumor, a disease, or cancer. Everyone that has aphasia is different, but their intelligence is intact.

So Tie, you don’t have aphasia. You won’t catch anything other than your toy or a snack!

And by the way, I don’t drink from YOUR bowl!!!

STILL
SOMETHING
2 SAY!



The Podcast of Aphasia
Awareness, Resilience
&
Encouragement

www.MoreThanAphasia.com



Hosted by:
Denise Mendez

“I MAY HAVE APHASIA, BUT
APHASIA DOES NOT HAVE ME!”

Fatigue After Brain Injury (including stroke)

Everyone experiences fatigue at some point. People with brain injuries (including those caused by strokes) commonly experience fatigue that is part of the recovery process, but it is a big barrier to participating in daily life activities.

Fatigue is more than just physical and mental tiredness. It has been described as exhaustion, lack of energy, and low vitality.

Symptoms of fatigue:

- Decreased ability to communicate effectively
- Decreased ability to engage in social activity
- Restlessness
- Moodiness/emotional
- Withdrawal
- Increased negative thoughts
- Lack of motivation and interest
- Difficulty engaging in daily activities

Aphasia Life: Neurofatigue

Neurofatigue is a common symptom of persons who have suffered a stroke or a traumatic brain injury.



If you are experiencing the symptoms of NEUROFATIGUE...

Contact your doctors- Primary and Neurologist!

Meet the Mid-Atlantic Aphasia Conference officers: Mark Harder-President, Jim Burd, Jenn Derry, Kevin Derry, Crystal Laughlin, Dorothy Laven-Secretary, Denise Mendez

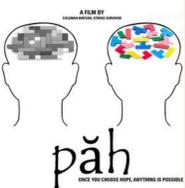
The MAAC Quarterly Calendar (January-March)

Aphasia Support Groups- Zoom Zoom

Monthly **every 2nd Mondays** at 7pm

Caregivers/Care Partners Groups-

Monthly **every 2nd Thursdays** at 7pm (unless a shared session with Monday)

Date	Session	Topic/Guest
January, Monday, 8th	Aphasia Support Group	Happy New Year- Reviewing the old year and planning for the new year!
Thursday 11th	Caregiver/Care Partner Support Group	*To Be Announced
February, Monday 12th	Aphasia Support Group	Guest: National Aphasia Assoc. Special Advisor Doreen Mendez
Thursday 15th	Caregiver/Care Partner Support Group	*To Be Announced
SPECIAL EVENT: MAAC Mini-Conference 	Saturday, March 2 nd 12 noon – 4pm Coleman Watson päh Documentary Bringing Science, Art, and Hope	Location: BUCKS COUNTY COMMUNITY COLLEGE – Newtown Campus 275 Swamp Road, Newtown PA The Gallagher Room 18940 https://www.eventbrite.com/e/maac-mini-conference-tickets-790611629667?utm-campaign=social&utm-content=attendeeshare&utm-medium=discovery&utm-term=listing&utm-source=cp&aff=ebdsshcopyurl
March, Monday 11th	Aphasia Support Group	Guest: Avi Golden
Thursday 14th	Caregiver/Care Partner Support Group	*To Be Announced