



Mid-Atlantic Aphasia Conference Newsletter

www.midatlanticaphasiaconference.org

Volume #1

Edition #2

April 2024

From The Editor's Desk:

Welcome back to the 2nd edition of the MAAC Newsletter. We are gratefully encouraged by feedback of our 1st edition. We are looking forward to sharing more stories, resources, and information.

What a busy quarter we have had! In January we started with a review of the year 2023. Your feedback is helping us planning for 2024.

In February, we hosted two special guests: the new **Executive Director** of the **National Aphasia Association**, *Maura English Silverman, MS, CCC/SLP and Tsgoyna Tanzman, MA, CCC/SLP.*

We appreciated *Mrs. Silverman's* transparency as she shared her lived experience as care giver for her mother who had a stroke and lived with aphasia and apraxia.

Ms. Tanzman shared strategies and ideas on helping our loved ones transition to the next stages of their lives after stroke and brain injury.

In March we hosted Avi Golden, who encouraged us with his stroke story, "No Barriers." Avi shared many resources for adaptive sports and physical activities.

Advocate for People with Aphasia

MAAC President – Mark Harder

I am back to say, "**Get the word out! Aphasia!**". I never heard the word "aphasia" until I had a stroke, and I didn't really understand the impact of the condition.



I would look at the magnet on the refrigerator and say, in my mind, "this is not me"! Six months later, in the "golden period", I realized that I am the man in the magnet. I wanted to know everything about stroke, aphasia, and the affects on my body, mind, and soul.

The problem was that I couldn't read, write, or listen to audible books. I needed help like asking family, friends, and other people to speak slowly, repeat if needed, and give instructions only one step at a time. Sometimes I needed space to move away from all simulations like noisy rooms and many people talking over each other.

Now I want to advocate for people with aphasia as I recover too. There are a lot of resources on the internet, but I enjoy meeting people with aphasia during Zoom aphasia support groups. We learn from each other.

Jim Burd worked on an Aphasia Wallet Card at Capital Health Aphasia Support Group. Denise Mendez introduced me to the imPACT Group of Temple University while we were at the Salus University Aphasia Support Group.

This is a resource that I found on the web, **Integrative Reconnective Aphasia Therapy - Education and Advocacy:**

https://www.iraphasiatherapy.com/_files/ugd/6428af_f8762f5632e044f3980e9bd2407f2b9b.pdf.

This is why advocacy means so much.

Let's get the word out! Aphasia!

From The Editor's Desk:

(continued)

The MAAC Mini-Conference was another great event. The weather on that date was bad, but Coleman Watson's documentary, **páh** - was AMAZING! When it is shown again, *be sure* in attendance. You do not want to miss this!

Be sure to check the Spring calendar (pg. 8) for all activities and support groups. We are so glad you are connected with us!

Denise Mendez



Reminder: World MoyaMoya Day is May 6th !



MoyaMoya disease affects about 1 out of every 1 million people in the United States. It is a chronic and progressive condition of the arteries in the brain. It leads to blockages, strokes, and seizures.

There is no cure for this disease yet. **MoyaMoya** is so rare and its' causes are not fully understood.

*We do know that **MoyaMoya** is passed down genetically.*

If you have a family member with **MoyaMoya** disease, your risk of having the condition is 30 to 40 times higher than that of the general population. Talk with your doctor to get more information.

On May 6th , please wear blue to support MoyaMoya awareness!

MAAC Support groups
for persons with aphasia
Virtual (on ZOOM)
Monthly every 2nd Mondays at 7pm

MAAC Support groups
for Caregivers
Virtual (on ZOOM)
Monthly every 2nd Mondays at 7pm

Observing Brain Injury Awareness Month

Since 1980, each **March**, the nation has observed **Brain Injury Awareness Month**. The Brain Injury Association of America (BIAA) leads with a simple vision-that everyone in the U.S. who sustains a brain injury is *recognized, treated, and accepted*. The mission of the association is to *improve the quality of life of people affected by brain injury and advancing brain injury prevention, awareness, research, treatment, education, and advocacy*.

There are more than 5 million adults and children in the U.S. living with some sort of brain-injury-related disability. Many of these injuries are a result of **strokes, infectious diseases, brain tumors, car and cycle accidents, falls** at home or on the job, **sport and recreation accidents**, and **assaults**. Some of the injuries are "**mild**" injuries called **concussions!**

On March 5-6, the members of the brain injury community met at on Capitol Hill (Washington, D.C.) for Brain Injury Awareness Day and to build awareness and advocacy and win reauthorization for the Traumatic Brain Injury Act.

Another TBI, Rehab, and a New Mission!

Jim's Story- Part 2 (Part 1 is included in the Jan 2024 MAAC Newsletter)

In July 2013, I went on the roof of one of the kennel buildings to repair the roof. I do not know what happened, but I fell off the roof and the left side of my head hit the concrete on the ground. My wife Debbie, who was an EMT, immediately called 911. The ambulance quickly arrived and rushed me to Capital Health Hospital in Trenton, NJ.

In the emergency ward, the neurosurgeon told my wife that it did not look very good from that impact on my skull and the brain. The surgeon opened up my skull in the same place that my 1968 surgery was. After the surgery, he told Debbie that the odds were not very good for me. I was told that I was placed in intensive care, and in due time I was starting to recover. I have no memory from when I fell off the roof, but I was breathing and improving.

Eventually I was sent to a local rehabilitation hospital. Debbie in three days saw that I was getting worse, not better. She asked the nurse for my medication and saw that it was typed incorrectly and they were giving three times more of the antiseizure medication.

Debbie immediately called 911 and took me back to Capital Health. They said that if I had another round of medication my heart would have stopped working. I recovered again and then Debbie had me sent to the JFK Rehabilitation Hospital in Edison, NJ.

I was recovering with some outstanding doctors, nurses and therapists. I attempted to get out of bed and fell and broke my left wrist, which eventually healed after surgery. Then with our insurance changing at the end of August, I had to leave JFK and Debbie had me taken to Magee Rehabilitation Hospital in Philadelphia, PA.

After three days there, I was told that I was in too good of health and I had to go home, BUT I had to come to Magee three times a week for therapy. Debbie and I would get on the train in West Trenton and go to Magee three times a week. I realized that I was getting better and finally said to Debbie that I could go to Magee by myself. We made an agreement that I would call her when I got into Philly and a few more times during the day. I remember saying to Debbie that my recall was improving but I still wasn't back to 100%.

Eventually my insurance had run out. I was back home and Debbie and I continued working on my therapy. We would go to a bookstore and get 1st and 2nd grade books, and I would try to read. A friend who was a retired reading teacher work with me. One day I read a local newspaper completely and then I hid it away. After five days of reading it I told Debbie that I had read the paper for five days; she was happily shocked. From there ,we contacted a graduate of a local college who we paid help me write again. I was getting better and better.

I remember going to a psychiatrist for testing my communication skills, and did poorly on the test. Six weeks later I went through the testing again, and again I did very poorly. At that point the psychiatrist said that I could no longer be employed. One day Debbie and I went to see my neurologist who smile at me while we were speaking, and I asked her why she was smiling. She said that she never thought that she would see me recover this well from the neurosurgery.



What a great Rehab you made, Jim and Debbie!

Look for the 3rd part of Jim's Story in the next episode of the MAAC newsletter!

Questions from Tie!

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



“Let’s Talk About Apraxia.”

Hi Tie! “Let’s talk about apraxia.”

Tie said, Practice? Practice? Practice!

“Not the game that I go out there and die for and play every game like it’s my last. Not the game. We talkin’ ‘bout practice, man!”

Tie, we are talking about **apraxia** not **a practice** and it’s not a game. You’re not Air Bud.

You know that I have aphasia. I have problems speaking and can’t remember how to retrieve words easily. Like me having a stroke, apraxia could be a result of a stroke, traumatic brain injury, dementia, brain cancer, or brain tumor. Apraxia is a little different though. It is a motor speech disorder that makes it hard to speak. The muscles in the mouth may be still strong but the brain may send the wrong movements of the mouth, tongue, lips, and air - speech is slow, groping for words, adding sounds, leaving sounds out, or making the wrong sounds.

So, practice is very important to recovery like brain games.

*Check out – [National Aphasia Association](#), [ASHA](#), [NIH](#)



Apraxia of Speech

Apraxia of speech (AOS) is a speech sound disorder. Someone with AOS has trouble saying what he or she wants to say correctly and consistently. The severity of AOS varies from person to person. It can be so mild that it causes trouble with only a few speech sounds or with pronunciation of words that have many syllables. In the most severe cases, someone with AOS might not be able to communicate effectively by speaking and may need alternative communication methods.



MAAC Mini-Conference

featuring
Coleman Watson's documentary
"păh: Bringing Science, Art, and Hope."

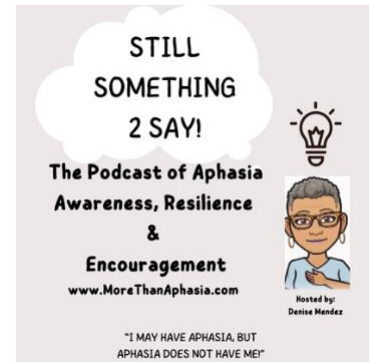
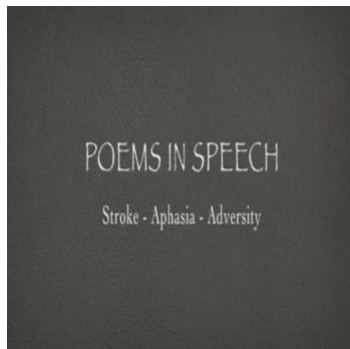
We met at the Bucks County Community College (Newtown Campus) from 12 noon -4:00pm. It was a great impressive mini-conference ... there were aphasia information tables sponsored by Capital Health, Moss Rehab., Salus University, PACT (Philadelphia Aphasia Community at Temple University) etc.

Everything went well (except the rainy weather)! We met new members in the aphasia community and enjoyed the popcorn and soft pretzels too!

"The păh documentary was so informative and did a good job explaining aphasia. I think everyone should see this film. It explained so much about aphasia. What really moved me was that statistic about the suicide rates among aphasia community." Crystal

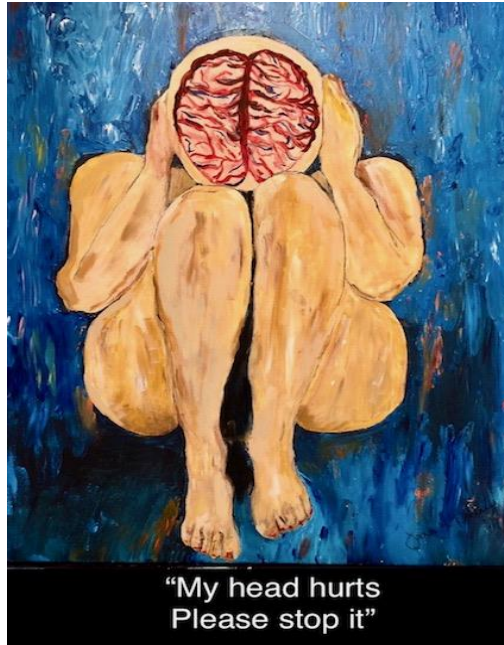
"Coleman Watson's, păh documentary was a living thread of inspiration and twenty warriors banding together. Making this film helped himself with Project Based Therapy as he helped others." Mark

" Hey Coleman, you had me at "păh!" Denise



Three Monkeys Café At Torresdale Station

Three Monkeys Café
EAT, DRINK, & BE MONKEY
Come for a unique dining experience. Pick your habitat: Risdon Ferry Dining Room, Monkey Court, Tree Bar & more!
9645 James St, Philadelphia, Pennsylvania 19114
3monkeyscafe.com



Jenn's Story

My name is Jenn Derry. Briefly, before my stroke my life was pretty hectic, stress a little, but happy. I had a great husband, a beautiful son and I was progressing my career. I was a director of operation to over project managements all around the USA, German, Japan and project coordination worded for a company that does clinical research for mental illness such as disorders of bipolar, etc.

It was the day after Mother's Day, May 9, 2016. I woke up feeling sick. I took my son to daycare and couldn't make it out of the parking lot when I threw up. I thought maybe it's a stomach virus. I tried to go home and sleep, but my husband kept calling me and waking me up to see if I was ok. But in a couple of hours, I were rushed to Saint Mary's Hospital. I don't remember much more after that, aside of hearing the propellers, from the helicopter ride to Jefferson hospital for a few seconds and I remember in the operating room someone began taking off my wedding ring, I remember trying to fight them not to take it off.

For a few days I was in a coma, and then...I woke up! I was alive!

I had an ischemic and a hemorrhagic stroke on the left side of my brain. It was so serious that I needed a craniotomy to remove the entire left side of my skull. The right side of my body has physical weakness, low vision and I have seizures and had global aphasia.

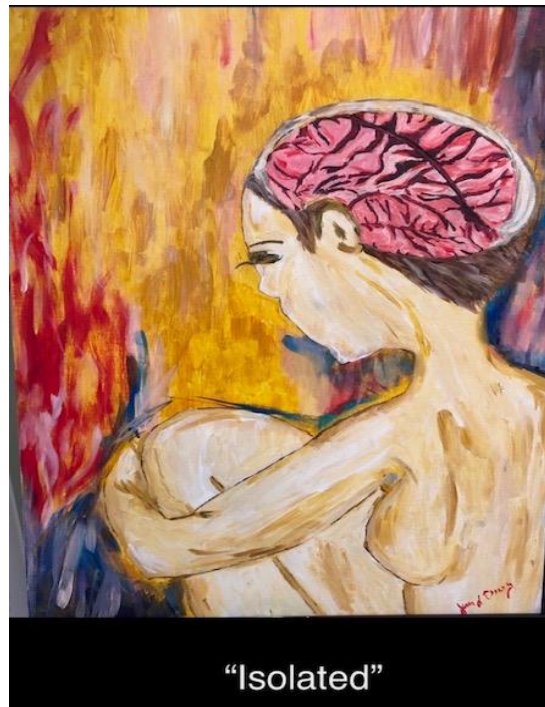
When it happened, I was young...my son was only 14 months old. I couldn't sing my baby a lullaby, read him a bedtime story and I could not say "I love you". I couldn't spell my name and couldn't understand my alphabet A-Z or even count 1 to 10.

I realized I had a long road ahead of me. This would be the beginning of a long and uncertain journey to recovery.

I started painting. Before my stroke I never painted. I wanted to find a way to express myself. The words were so difficult for me, and I tried to paint. It became my therapy.

I felt bottled up in my head sometimes, so it had been a way to show my feelings in a creative way. I can't write a journal, I can't read or speak properly, so painting became my journal.

After having my stroke and having aphasia I wanted to provide help and to support MAAC. Advocacy for aphasia is a powerful movement aiming to spread awareness.



APRIL							MAY							JUNE						
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21	22	23	24	25	26	27	26	27	28	29	30	31	23	24	25	26	27	28	29	
28	29	30											30							

The MAAC Quarterly Calendar (April, May, June)

Date	Session	Topic/Guest
Monday, April 8 th at 7:00pm	Joint Support Group for people with aphasia and CareGivers (on ZOOM)	<i>Painting with Alpha Creations</i> By Ardena and Debra
Thursday, April 11 th at 7:00pm	Caregivers Support Group (on ZOOM)	Open to all caregivers
Saturday, April 13 th at 12noon -2:00pm	Women's Health Fair at Mt. Airy COGIC 6401 Ogontz Ave. Philadelphia	MAAC & Aphasia Awareness
Saturday, May 4 th at 8am-11am	Community Yard Sale at the Center School 2450 Hamilton Ave. - Abington, PA	MAAC & Aphasia Awareness
Tuesday, May 7 th at 4:30pm-7:00pm	Adler Aphasia Center's "GETTING THE WORD OUT" Community Fair Free Temple B'Nai Shalom 300 Pleasant Valley Way West Orange, NJ 07052	MAAC & Aphasia Awareness
Monday, May 13 th at 7:00pm	Support Group for Person's with Aphasia (on ZOOM)	<i>Special Guest Jerry Wald</i>
Thursday, May 16 th at 7:00pm	Caregivers Support Group (on ZOOM)	Open to all caregivers
Sunday, May 19 th at 12 noon	Bristol Borough Sunday Stoll	MAAC & Aphasia Awareness
Monday, June 10 th at 7:00pm	3rd Virtual Mid-Atlantic Aphasia Conference	Aphasia Support Groups, Researchers, and Centers
Thursday, June 13 th at 7:00pm	Caregivers Support Group (on ZOOM)	Open to all caregivers
Sunday, June 23 rd	Annual Aphasia Get-Together at the Bristol Amphitheater	<i>Siobhan Hutchinson</i> <i>Holistic Health Techniques</i>

GET THE WORD OUT! APHASIA!