

## Mid-Atlantic Aphasia Conference Newsletter

www.midatlanticaphasiaconference.org

Volume #2 Issue #1

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#### From The Editor's Desk:

### A New Year and A New Commitment!

Happy New Year Friends! A new year is a time for fresh beginnings. It is a good time to reflect on the past, and a chance to make a new commitment to ourselves for our future!

Here is a quote I read...

"New year – a new chapter, new verse, or just the same old story?

Ultimately, we write it. The choice is ours." – Alex Morritt

As a person with aphasia who is working hard to reclaim her writing skills- I like the comparison of my new year goals or resolutions to *new parts of our life story*.

As we ended year 2024, we in the aphasia community have been thinking about goals, intentions, and plans for year 2025!

Let's each commit to our own selves that we will:

- Make manageable changes- so we will not get overwhelmed by a new goal
- **Build habits gradually**-consistency is important, daily, weekly, etc.
- Track your progress-journals, charts, calendars, or apps on your phone or computer can help you "see" your progress
- Celebrate small wins -recognize and reward your progress

Let's make it the best year yet!

Denise Mendez



### New To M.A.A.C.?

Welcome to the Mid-Atlantic Aphasia Conference!

We welcome you to contact us and connect with us!

You are invited to join our **Support Group sessions** (7pm EST every 2<sup>nd</sup> Monday)

&

Conversation Group sessions (7pm EST every 4<sup>th</sup> Monday)



Scan this QR code and subscribe to get our emails and to see our website

https://midatlanticaphasiaconference.org

for useful information, photos, and calendars!



# **MAAC 2025**

Happy New Year to our aphasia community!

**MAAC** has a lot planned for this year. Some things will change but for the better.

The **2<sup>nd</sup> Monday of the month** will still be the Zoom Support Groups **at 7:00PM ET** – with Awe-Inspiring Special Guests like Mert Robinson (January), Bruce Farrell (February), and Kevin Rhinehart (March).

Changes are that **MAAC** will add the **4th Monday of the month at 7:00PM ET** on ZOOM with more time to share your experiences and company. During this time, Caregivers/Care Partners will have a break-out session!

SAVE THE DATE! Saturday, April 26<sup>th</sup> is the date of the MAAC Mini-Conference at the Bucks County Community College. We will email you information and post on the website SOON!

MAAC will add more In-Service Sessions for Physical Therapists, Occupational Therapists, Speech Therapists, Speech Grad Students, and other care partners!

We look forward to additional activities and "face-to-face" opportunities such as the "Get Together", Phillies Aphasia Advocacy Game, and the Holiday In-Person/Zoom Celebration.

### Can't wait to see you!

Mark Harder President

### Care Givers/ Care Partners Corner

## TAKING CARE OF YOU IS ESSENTIAL, TOO!

(from Health Monitor Living 2024)

Caregivers often must juggle life, work, and caring someone with aphasia. The following are tips for avoiding caregiver burnout!

- Set calendar reminders.
  - o Block off time for things you enjoy-
    - Going out to dinner with friends
    - Reading a book
- Find outlets for tough emotions-
  - Connect with local support groups
  - o Investigate social media channels that are appropriate
    - YouTube, etc.
- Treat yourself!
  - Set a goal date and save a small amount of money each week or month to go toward to a splurge!
    - For a coffee or lunch date with a friend
    - A massage at a local spa
- Write a list of "helps/needs".
  - Errands and tasks that others can help with
- Enjoy nature.
  - Take daily breaks outdoors to destress and recharge. (The American Journal of Preventative Medicine states that walking as little as 20 minutes a day can reduce stress hormone and extend your lifespan).

### Take Time For You! You Are Worth It!

### A Resource:

### **Brain & Life Magazine**

Neurology For Everyday Living

https://myBLsub.com

The magazine is available in print (mailed to your home) 6x/year and on-line.

Also available in Spanish!



### Laughter Is The Best Medicine!

**Bobby**: Does exercise help a person with aphasia make better decisions?



**Sunni:** Yes, I ran a mile on Monday and decided, "Never again!"

### **Tie Can Feel Your Presents**

Well, the holidays are done, and a new year starts but Tie can still feel your presents.

He feels your warmth.

He feels your good vibes.

He feels your peace and your love.

These are the presents that always give.

Aphasia effects your presence and your absence. Get engaged. If you are sad or lonely, ask for help. If you can't help yourself, be the present.



# An Aphasia Community Feature: Jennifer Ciraolo's Story

### \*\*July 25, 2010 - A Life-Changing Day\*\*

July 25, 2010, is a day I will never forget. It began like any other workday as a Fish, Game, and Wildlife Officer—a role I considered my dream job. Halfway through my shift, the skies turned cloudy. While walking back to my truck, lightning struck a nearby tree, and then it struck me. The lightning entered through my feet, exited through my head, and wreaked havoc on everything in between including my work truck.

The aftermath was life-altering. I was bedridden for over eight months and could barely move without assistance. Even the simple task of rolling over became a monumental challenge; I had to force myself to crawl to the bathroom just to avoid asking for help. **Lightning** didn't just damage my body, it disrupted my brain, and since the brain controls everything, nothing functioned properly.

### \*\*Neurological Struggles\*\*

The most significant ongoing issues I face are neurological. Speech and memory remain my greatest challenges. I struggle with processing information; while I can understand things when they're explained, I cannot retain them. Learning new skills feels like an endless cycle of understanding and forgetting.

Initially, my limbs and head felt numb. Parts of my head and fingers lacked sensation, and my legs felt like stilts—heavy and uncooperative, as if weighed down by ten pounds of mud. My hands, eyes, and head twitched involuntarily, though these symptoms have mostly subsided. Now, involuntary twitching occurs only during intense concentration, like when I'm drawing.

For years after the accident, I experienced aphasia, which made speaking and communicating nearly impossible. Even now, I prefer text or email rather than engage in verbal conversations.

### \*\*The Road to Recovery\*\*

Recovery has been long and difficult and is still ongoing. I spent about 10 years in cognitive therapy, which helped immensely, but my insurance no longer covers it, so now I must navigate recovery alone.

Support groups are scarce, especially for lightning strike survivors, as most don't survive incidents like mine.

In my case, the lightning hit a tree 6–8 feet away, entered through my feet, exited through my head, and traveled into my work truck about 5 feet away. The truck's electrical system was fried, but its proximity likely saved my life. If the lightning had passed directly through me without the truck, I wouldn't be here today.

Though I am far from the person I was before the accident, I've come to accept my limitations. Dressing myself is still a lengthy and difficult process, and I continue to struggle with showers and daily activities. Eight years after the accident, I was finally able to manage things on my own, but my life is far from "normal." Everyday to function, to get through the day, can still be a struggle.

Continued- Jennifer Ciraolo's Story

### \*\*Unpredictable Challenges\*\*

The unpredictability of my condition is one of the hardest aspects to manage. Each day feels like a gamble—some days I can read, while on others, I can't. My motor skills fluctuate; on bad days, I don't know where my hands or legs are, and they refuse to follow my commands. I still bump into walls if I walk too quickly, and my gait has permanently changed. On particularly dizzy days, I tend to lean backward to the right—a quirk my partner affectionately calls the "lean back," referencing the song. Humor has become an essential coping mechanism.

### \*\*Perspective and Gratitude\*\*

Years ago, I couldn't have described these challenges because I lacked the words or ability to express myself. Visits to doctors were frustrating because I couldn't explain what was wrong. Now, I'm grateful to have a voice, even if finding the right words can still take time.

Focusing on what I've lost or can no longer do only leads to dark days. Instead, I celebrate small victories, no matter how insignificant they may seem. Early in my recovery, my cognitive therapist taught me to accept limitations and acknowledge when I truly couldn't do something. Letting go of the person I used to be was one of the hardest lessons, but it was necessary for my emotional healing.

Even though I occasionally throw myself a pity party, I refuse to stay there. Each day is a step forward, no matter how endless or pointless the journey feels.

### \*\*Finding Joy Again\*\*

This summer, I turned 44, but my body feels like it belongs to someone twice my age. Having lived with these challenges since I was 30, I've had to adapt and focus on what I can still do—like drawing. It takes me much longer than it used to, but I persist until I figure it out.

Life after a lightning strike is an ongoing struggle, but it's also a testament to resilience and the human spirit. Every step forward, no matter how small, is a victory worth celebrating. And, with the help and support of my loving sister, Justine, who forever was and always will be my light.

JC





Eclipse Pet Portraits

<a href="https://eclipsepetportraits.wordpress.com">https://eclipsepetportraits.wordpress.com</a>
<a href="mailto:Eclipsepetportraits@gmail.com">Eclipsepetportraits@gmail.com</a>





## The First MAAC Winter Holiday Dinner - Aphasia Mystery Event!

















## MAAC QUARTERLY SCHEDULE/CALENDAR

# January, February, March 2025

Date	Session	Topic/Guest
2 <sup>nd</sup> Monday, January 13 <sup>th</sup> at 7:00pm	MAAC Support Group For people with aphasia and care givers/care partners On Zoom	Special Guest <b>Mert Robinson</b> ToastMasters'
4 <sup>th</sup> Monday, January 27 <sup>th</sup> at 7:00pm	MAAC Conversational Group For people with aphasia and care givers/care partners On Zoom	
2 <sup>nd</sup> Monday, February 10 <sup>th</sup> at 7:00pm	MAAC Support Group For people with aphasia and care givers/care partners On Zoom	Special Guest <b>Bruce Farrell</b> His Words: Brain Injury
4 <sup>TH</sup> Monday, February 24 <sup>th</sup> at 7:00pm	MAAC Conversational Group  For people with aphasia and care givers/care partners  On Zoom	
2 <sup>nd</sup> Monday, March 10 <sup>th</sup> at 7:00pm	MAAC Support Group For people with aphasia and care givers/care partners On Zoom	Special Guest <b>Kevin Rhinehart</b> Life History Book
4 <sup>™</sup> Monday, March 24 <sup>th</sup> at 7:00pm	MAAC Conversational Group For people with aphasia and care givers/care partners On Zoom	

# **GET THE WORD OUT!! APHASIA!!**



SCAN FOR MORE INFORMATION!