Colorado PCA Support

QUARTERLY NEWSLETTER

https://medschool.cuanschutz.edu/pca

Contact Us:

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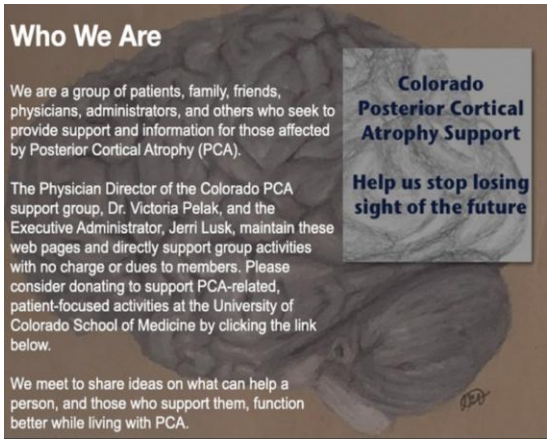
CO PCA Website



To Donate:

Brain & Vision Fund: Provides funds for posterior cortical atrophy research and support.

Brain Donation:
To learn more about the gift of brain donation.

UPCOMING EVENT

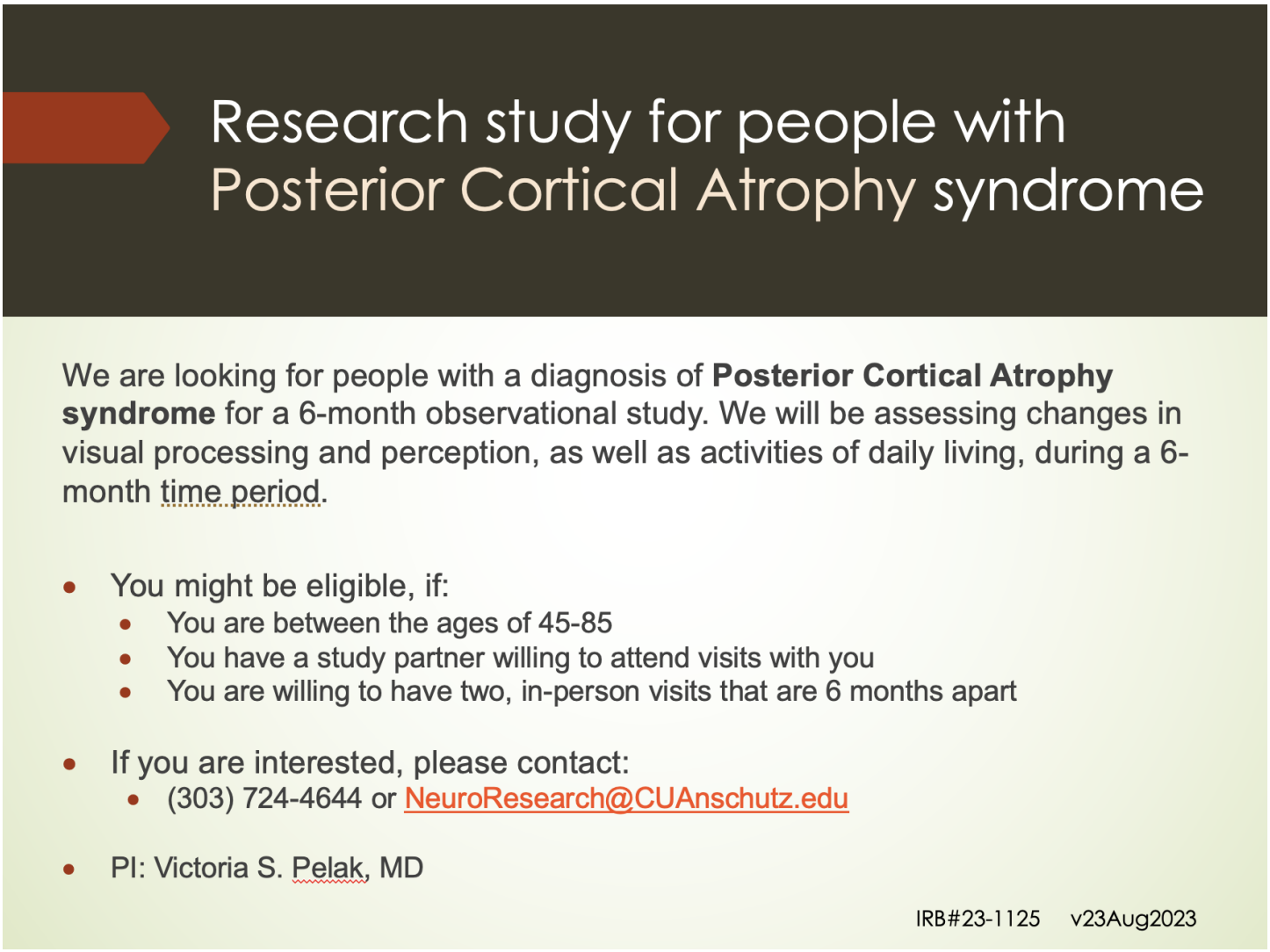
Colorado Posterior Cortical Atrophy Support Group Webinar

December 6, 2023 – 2:15 pm – 3:15 pm (MST)

Part 1: Struggles With the Use of Technology in PCA

A new study on longitudinal changes in Posterior Cortical Atrophy at the University of Colorado School of Medicine has launched.

A major roadblock for developing effective treatments for PCA is the lack of longitudinal outcome measurements tailored to the unique features of the PCA syndrome. Specifically, there is a crucial need for assessment tools that can effectively capture the evolving symptoms and signs of PCA over time. Current measures for Alzheimer's disease treatments often concentrate on memory and rely on visual function, proving either insufficiently sensitive to temporal changes or too demanding for individuals with PCA. Without specialized outcome measures, determining the efficacy of treatments becomes an insurmountable task. Our research group is dedicated to addressing this gap by developing and assessing precise tools designed for tracking temporal changes in PCA signs and symptoms. A new longitudinal study at the University of Colorado marks an essential initial stride towards understanding these changes and, ultimately, being able to use this information to develop and assess treatments for PCA patients. Below is the advertisement for our study with contact information if you are interested.



Precision Medicine – Dr. Richard Isaacson

Dr. Richard Isaacson, with the Institute for Neurodegenerative Diseases in Florida, gave a lecture at our CO PCA Support Group on August 9th (Click HERE for the Aug 9th CO PCA video) about prevention of cognitive decline for diseases that lead to dementia. During Dr. Isaacson's lecture, he reviewed resources.

Below is a list of those resources:

- www.brainmind.org/alz - *Mastering Brain Health Course*, by Dr. Richard Isaacson (view Dr. Isaacson speaking about this on the CO PCA Webinar video at 46:34 min)
- www.AlzU.org – *Alzheimer's Universe*, by Dr. Richard Isaacson. 2.5 million people have signed up and it is one of Dr. Isaacson's proudest works. It is knowledge for the public, high-schools, college students, medical students, doctors, and neurology trainees with many free webinars (view Dr. Isaacson speaking about this on the CO PCA Webinar video at 47:11 min)

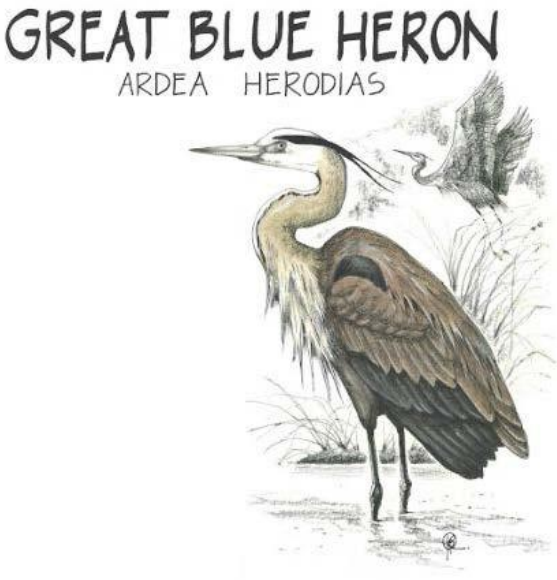
NIH Funded Study – *Retain Your Brain*

This is an NIH funded study that Dr. Isaacson's group will be running that will use Smartphones to measure the effectiveness of software to manage Alzheimer's risk factors (view Dr. Isaacson speaking about this on the CO PCA Webinar video at 45:37 min).

Goal of Study: This is an NIH funded study at https://retainyourbrain.com/#!/ and is a way to use software that they have programed with initial elements of Artificial Intelligence to take a person's risk factors through the phone, do memory tests through the phone, and a subset of people will get blood draws. It will be a 6-month study that will launch around mid to late September 2023.

REWIND

Living Well with Dementia: The Nature of Nature is Change



The Colorado PCA Support Seminar held on April 5, 2023, featured a video presentation followed by questions and answers by members Todd and Marianne Ballantine. The video was adapted from an original presentation at an Alzheimer's Association local meeting in November 2022 during National Alzheimer's Disease Month & National Caregiver Month. In 2016, Todd was diagnosed with Posterior Cortical Atrophy (PCA), and he and his wife Marianne have worked to face his journey with PCA using his motto that "The nature of nature is change". Todd is an environmental scientist and specialized in natural resource conservation while leading his firm, Ballantine Environmental Resources, for over 30 years in Boulder, Colorado, and Hilton Head Island, South Carolina. Todd is also a Pulitzer Prize nominee for his writing about the environment. He authored and illustrated "Tideland Treasure, A Naturalist's Guide to the Southeast Coast", and one of his illustrations is shown above.

At his Colorado PCA Webinar, Todd and Marianne discussed how nature's diversity allows for opportunities and that nature demonstrates the amazing "workarounds" to challenges. Todd discussed how everyone has the capacity to use their brain's potential to adapt to the ever-changing set of rules one must live by, even in the setting of PCA and dementia. Todd and Marianne emphasized that nature teaches us that there are "…opportunities for many different forms and states to live well" during a lifetime. Finding another way or finding a "workaround" is within our reach, just as nature demonstrates every day. A pertinent example today with extreme weather and wildfires can be found in trees such as the Lodgepole pine that have cones that are dependent on fire to open for seed dispersion. Todd and Marianne reminded us that we are greater than the disease that might impact us.

"We can use nature's lessons of adaptability to live well with dementia." –Todd Ballantine

We look forward to using their advice to continue to help people overcome the many challenges that PCA brings and to remind those impacted by PCA that challenges can also be considered opportunities to adapt and learn to live well. We thank Marianne and Todd for sharing their wisdom and providing us with a reminder that nature can help ground us, even in difficult times.

Click **HERE** to watch the CO PCA Support Group video

Questions from Care Partner members of the Colorado PCA Support Group Answered by Dr. Christina Vaughan, Associate Professor of Neurology, Section Chief of Neuro-Palliative Care at the University of Colorado

(Many of the resources below pertain to Colorado, but may be searchable in your city/state)

Question: In dealing with PCA as a care partner, I am so stretched and extended that there isn't much, if any time, for anything except taking care of my husband, working, being somewhat there for our kids, trying to carve out some kind of social life, and getting some sleep. Everyone in the PCA Support Group webinar voiced a need to figure out things for our PCA persons to "do". So much has been taken away from the patient and there just isn't that much for them to do. It seems like many of us are dealing with spouses or partners or parents who were very active and passionately involved with many interests.

Answer: Despite the many challenges and changes that can arise when living with PCA, there are still ways to find enjoyable activities. Some ideas include:

- **Music therapy** Joining a walking group to help keep someone with PCA active and sociable – look out for local dementia-friendly walking sessions.
- **Reminiscence work** – share your life experiences and stories from the past with photos, objects, video, and music clips, either as a book or on a tablet or other digital device. Given frequent challenges with vision, music clips and objects may be the best place to start.
  - Create a personalized playlist: https://www.playlistforlife.org.uk/
- **Memory cafes:** A Memory Cafe is a wonderfully welcoming place for individuals with Alzheimer's Disease or any other form of dementia, or other brain disorders. They are designed to include the care partner as well, for a shared experience. Additionally, it is helpful for people with all forms of mild cognitive impairment (MCI). Individual Memory Cafes focus on different aspects for a unique experience. You may find some are activities-based, while others focus on education. You might have one enjoying the connections of demographic-appropriate music and dancing. Others might focus on crafts and painting, while some facilitate informal conversation to create new friendships. Some simply guide the participants in exercises that foster reminiscing. Can be in person or online.
  https://www.memorycafedirectory.com/memory-cafes-in-colorado/
- **SPARK** connects guests with early memory loss and their families to cultural experiences and meaningful connections through the Alzheimer's Association and a variety of museums and community partners. Enjoy an interactive and engaging experience in a comfortable setting, guided by trained docents and volunteers. Programming at each venue is different. The relaxed atmosphere is welcoming and stimulating. Attendance of multiple programs in different locations is encouraged!
  https://www.sparkprograms.org/
- **Equine therapy in CO:** provide mental health therapy services incorporating horses to individuals and groups. They also give horses no longer suitable for their original purpose a new "career" by training them to be therapy horses.
  https://www.equinetherapyco.org/
- **Adult education** – they develop several new topics every month (world events/topics and music)
  https://activeminds.com/
- **Cycling Without Age Littleton** - Trishaw rides - similar to a rickshaw, a 3-wheeled vehicle with pedals. A way to experience being on a bicycle in a safe way, without having to pedal or navigate.
  https://cwalittleton.com/

Part 2 - Continued – Q&A Dr. Christina Vaughan

- **A Wiser Mind** - emotional care and cognitive therapy for individuals and families living with depression, anxiety, Alzheimer's, and mild-brain injury.
  Http://awisermind.com/
  Phone: 888-982-9899

Question: I am also dealing with a lot of apathy – challenging to get my husband to shower and change (got him an electric shaver this year for his birthday), challenging to bring in any help, challenging to keep him "contentedly engaged", especially when he gets frustrated that all he can do is walk, listen to music and watch television.

Answer:

- Sometimes it can be helpful to "name" the apathy – label it, call it out as a symptom (and not someone's fault) and seek to externalize it, and then it can be easier to do something about.
- Set up a daily routine or schedule to follow, and keep this visible (e.g. use of calendars, clocks, watches, whiteboard).
  - On shower day, can announce 'It's time for your shower, the water is running and it's nice and warm' and hand them a towel.
- An overall loss of interest or motivation might be addressed by the following (adapted from https://onlinegrad.baylor.edu/resources/identify-address-apathy-and-dementia/):
- Identify where they find joy: Consider which activities have provided fulfillment for the person in the past. Art can be a good way to engage. A simple act like playing their favorite music may be helpful.
- Reminisce and ask questions about the past: Engage their long-term memory. If the person is interested in sports, for example, ask them about memories they have playing the sport or who their favorite players were.
  Introduce small amounts of activity at a time: If the activity is overwhelming, learn to be flexible and adjust it. They may be able to still do things that they have previously enjoyed if they are less involved.
  - Break tasks down into simple steps.
- Emphasize the process over the outcome: Pressure to finish an activity may inhibit desire to start it. Help them to initiate and allow them to enjoy the process.
- Be clear when you are communicating with them and use a gentle tone. Do not discuss deficits or declines or focus on what the person can't do.
- Provide positive feedback: Focus on what they can do, what they like to do, and how you can involve them in those activities. Set them up for success in an activity and make sure they feel included and rewarded for trying to participate.
- Caregiver Training: Depression/Apathy | UCLA Alzheimer's and Dementia Care Program: https://www.youtube.com/watch?v=H8oCzk1TCdg

Question: My husband's ability to work ended 8 years ago. He stopped being able to play the guitar 4 years ago, no sports, etc. What we did do right after he was diagnosed was travel as much as we possibly could while he could do it–rode horses and camped out through Mongolia for ten days, rode in Iceland for 10 days staying at hiking huts, traveled to Myanmar when it was open to work with a photographer to take the most fantastic pictures. Early on it was all about making memories. We took each one of our kids separately on an adventure trip so they would have one on one memories while he was still active. Those memories have totally stuck with him and the photographs are treasures. Obviously, not everyone can afford such luxuries. I worked really hard to make it happen, and I continue to work and am now totally frightened by the cost of home health care that we will face in the future. I DO KNOW that having a group of people battling this with me is a terrific support.

Answer on next page

Part 3 - Continued – Q&A Dr. Christina Vaughan

Answer: In addition to some of the ideas in Q1:

- Traveling tips:
  - https://www.alz.org/help-support/caregiving/safety/traveling
  - https://www.caregiver.org/news/navigating-travel-loved-one-who-has-alzheimers-disease/
- Read aloud from a favorite book you both enjoy
- Put photos of family members in an album or create a collage
- Listen to music together or sing favorite old songs
- Plant seeds and tend to the plants
- Eat ice cream together and talk about favorite flavors
- Watch a favorite old movie or television show and discuss favorite characters
- Play with finger paint, playdough, or magnets
- Talk about animals
- Talk about favorite sports

Great resources regarding activities which can spark and/or make memories:

https://www.alzark.org/wp-content/uploads/2015/03/Memory-Book.pdf (Downloadable pdf)

Question to Dr. Pelak from a member of the Colorado PCA Support Group

Question: Will all PCA patients eventually experience hallucinations? If so, at what point in the disease process will this likely occur? What sort of treatment is recommended for hallucinations and how successful is the treatment?

Answer: No, not all people with PCA will experience hallucinations. Few reports exist regarding the true prevalence but the estimate ranges from 10-25%. Thus, fewer than 2-3 in 10 people with PCA experience visual hallucinations. Some underlying diseases that lead to PCA are more likely to cause hallucinations. For instance, people with dementia with Lewy bodies have a 75% chance of experiencing visual hallucinations. It is important to know that if you develop hallucinations, this does not mean that you have dementia with Lewy bodies.

Most often, hallucinations occur in the late stages, but some people might experience the hallucinations at onset or within 1-2 years of the onset of PCA. If you experience hallucinations, it is important to tell your neurologist.

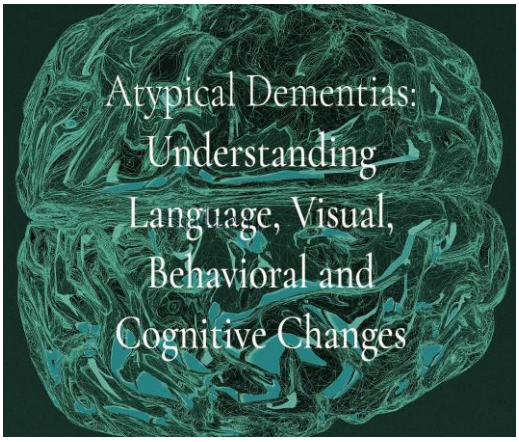
The first approach, before considering treatment, is to determine whether a factor (or factors) other than PCA is contributing to hallucinations. Once those are addressed, if present, the next step is to determine the impact the hallucinations have on the person experiencing them and their care partners. If the hallucinations are not disruptive, then there may be a role for non-medication approaches. If the hallucinations are intrusive or provoke anxiety or behavioral changes, medications should be considered.

Recently released, "Atypical Dementias: Language, Visual, Behavioral, and Cognitive Changes" is a newly published book featuring stories about PCA

By author Jamie Talan

Jamie Talan is a science writer specializing in the brain. The first two decades of her career was spent in the newsroom at Newsday. Her stories have appeared for the last twelve years in Neurology Today, a publication of the American Academy of Neurology. She is the co-author of "The Death of Innocents," that won an Edgar Award for best non-fiction in 1998; and Deep Brain Stimulation, published by the Dana Press. She is an assistant clinical professor at The Zucker School of Medicine at Hofstra/Northwell, where she started the art & literary journal — Narrateur: Reflections on Caring. She was editor-in-chief for the first ten years and stepped down in 2020, following a poignant COVID issue. She lives in Idaho, where she and her husband are sheep farmers and cattle ranchers.

To Purchase a copy of Jamie Talan's book Click HERE



In the past, Ms. Talan invited clinicians and researchers to give talks on PCA for patients and their families and recorded them. The recordings are an outstanding educational resource. See the link to the right to go to the recordings. You can also find a link to the series on the CO PCA Support Webpages.

To view PCA lecture series curated by Jamie Talan: click HERE

Posterior Cortical Atrophy Syndrome and Firearm Safety

An important concern about firearm safety can arise for those with the PCA syndrome and their family and friends. We know that diseases that cause the PCA syndrome, such as Alzheimer's disease and dementia with Lewy bodies, do result in safety issues regarding handling and storing a firearm that might not be evident to a person with PCA or their family and friends. For those with PCA syndrome, there are added concerns related to visual perception and decreased fine motor skills, referred to as 'apraxia', that occur early in the course despite memory, language, and judgment remaining without significant impairment.

However, determining how perception impacts judgment is not always evident to a person with PCA or their loved ones. We also know that some people with PCA have abnormal sleep patterns that can decrease judgment or cause a person to act out dreams while they are sleeping. When one considers these facts, and that handling a firearm in haste cab be very difficult for someone with apraxia and visual perceptual problems, then the risks for injury become greater than potential benefits of using and storing a firearm.

Taken all together, these issues that come together in the "heat of the moment" can cause unintentional self-injury or injuries to others with severe consequences.

Although there is not a one size fits all approach, having a firearm at home or continuing to use a firearm after a diagnosis of PCA or dementia should be discussed with your physician. Further support and discussion can be sought from other experts, including the Alzheimer's Association, which has tip sheets regarding firearms and the pdf can be found here (downloadable pdf) Additional information can be found on the Alzheimer's Association website. See below for an excerpt.

Ultimately, keeping an open dialogue with family and friends and medical experts will be important for your safety and for the safety of all those in the community.

ALZHEIMER'S ASSOCIATION

Firearm safety

Firearms and other weapons can be found in households across the country. In most situations, their presence creates no problems for responsible gun owners and others in the household. However, if someone in the home is living with Alzheimer's or another dementia, firearms can pose a significant risk for everyone.

For example, as the disease progresses, the person may not recognize someone he or she has known for years and view him or her as an intruder. With a gun accessible, the result could be disastrous. Even if the person has past experience with guns, his or her current abilities will be altered because the safe use of firearms requires complex cognitive abilities and quick decision-making skills, which may be compromised due to dementia.

Coping: An open letter to members of the Colorado PCA Support Community
Sent via email in the past and published here
By Maureen Foster, a long-time member of Colorado PCA Support

[*Below you will find an open letter to the community from Maureen Foster, who has been living with PCA for several years. Her goal is to share and learn more about how everyone is coping with PCA. We are happy to share her letter with the community. If you would like to respond, please email copca@cuanschutz.edu and it will be forwarded to Ms. Foster.*] [Note: you can ask to not have your name and email shared with Maureen.]

I would like to know how others with PCA manage their lives. For instance –

1. Is anyone working?
2. How many years have you had PCA and how has it progressed and changed?
3. What tasks can you handle?
4. At what point are you unable to do certain basic things, like getting dressed, etc?
5. At what point did you have to give up cooking and why?

I'm wanting to know more about what my future may hold. Someone who is ahead of me in their diagnosis can show me what may be in store for me, although I know it's very different for everyone.

For me, I was diagnosed 7 years ago. I was profusely confused and distraught at my diagnosis about how to manage daily life. I was on an anxiety med called Sertraline which helped, and after two years or so I didn't feel it was a necessity anymore. The anxiety had been about finances and deep management of not losing my house, the lack of driving, etc. It was all very overwhelming and difficult. I've been so independent my whole life, so the change was immense. The loss of independence is extremely difficult. When people step in to help me, it's much better when they do so after I ask. I still want to do as many things on my own as possible.

In the early stages, I was very inquisitive about the condition and how to manage things, but now I'd rather spend my time still discovering if I can manage things on my own. I love baking, cooking, sewing, and gardening. I can still garden, although it's difficult. I can no longer sew at all, which is a big loss. The simplest cooking is still possible, but more complex recipes are too difficult without assistance. My organizational skills were excellent and are now defunct. For example, filing paperwork – my son claims it's unnecessary to keep documents, but my old-fashioned self needs tangible items – that I can't even see [ha ha]. Filing is super hard. Technological devices could help, for example an identifier pen that can read the title of a physical document or read the file folder heading but acquiring that technological knowledge can also be difficult. All in all, it's very hard to organize without assistance.

For a period of time, my eyes felt better/more operational; however, I somehow lost the ability to read my phone recently. Seems like my far sight has improved but my near sight has worsened. Some days I can see better than others. It fluctuates depending on light, if I've eaten, if I'm tired, and so many things. I've also had bouts of leg issues that have now ceased. Early on, I had upper head movement. It was like I could feel something moving across on the inside of my forehead, but that sensation has now gone away.

On weekends, I have family help with grocery shopping, transportation, etc. During the week, I have a caregiver come one day for 3.5 hours to assist in reading me my emails, mail, calendar organizing, and any other chores that I need help with (including writing this essay as I dictate). The calendar on my iPad is much better for me than a wall calendar.

Technology will be an important factor in how we manage living with PCA. If one can use Alexa and other AI tools, a certain level of independence and self-soothing can be maintained. I use Alexa to keep me updated on events, weather, tell me stories and podcasts… I think of Alexa as a good friend.

Talking Books from the Library of Congress has also been wonderful.

Another incredible resource is the Center for People with Disabilities (CPWD). I've learned how to use a cane (and received a free one). They give a lot of information and insight into technology for the blind, such as smart phones made for low vision/blind use. I didn't know all the capabilities of my iPad until the CPWD showed me. I attend their support group "Don't Let Low Vision Get You Down", and an in-person monthly group also for low vision seniors. Click HERE for their calendar.

My special network of former coworkers, neighbors and friends are my coffee klatch. My siblings and kids keep me busy with family events and activities. My drive for independence has helped me keep a positive attitude towards my future. My stubbornness, you could say, keeps me in a state of possibilities even amid the dilemma of diagnosis.

---Written by Maureen Foster, May 2023

From Our Colorado PCA Support Group and Community Around the Country

Our PCA Group Members share insightful articles with us from time to time, and we want to provide stories and links to these stories.

NOTE: The opinions expressed in the articles do not reflect those of the PCA Support Group or the University of Colorado.

Mike Dickens, who has PCA, holding his grandson Teagan and enjoying a special connection

Click on Box Below

Also sent by Pat Demarest, an article you might be interested that was in the Durango Herald ***"It's not about the checkbook"*** by Kim Martin

Connecting the dots...
Durango Dementia Coalition

Our mission is to connect the dots to improve care and resources in Durango and the Four Corners region.
Have you or a loved one been diagnosed with dementia?
Are you struggling to find local resources?
Visit our website!

LaPlata County Helping Those with Dementia. CO PCA Support Group member, Pat Demarest, sent this and asked that we share with you to share with others - "Any help gets us closer to our goals. Thank you for your kindness and support, the Durango Dementia Coalition" Click **HERE**