Colorado PCA Support

QUARTERLY NEWSLETTER

Colorado Posterior Cortical Atrophy Support

Help us stop losing sight of the future

Our Vision

To be a beacon of hope and refuge for all persons affected by Posterior Cortical Atrophy

Our Mission

To serve those affected by Posterior Cortical Atrophy by providing in-person meetings and a virtual space for support, information, and resources

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WHO WE ARE

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Share your thoughts and stories with us by emailing

Brain & Vision Fund for Posterior Cortical Atrophy

UPCOMING EVENTS

CO PCA Support Group Webinar

Our next PCA Support Group Webinar will be on **December 7, 2022**. Dr. Pelak will update everyone on the latest news in PCA and our special guest is Christine Morrisey, BS, who volunteers with the Massachusetts/New Hampshire Alzheimer's Association Chapter and will facilitate a support group discussion for people with Posterior Cortical Atrophy, their families, friends, and care partners. An invitation has already been sent out to the PCA Email group, but if you did not receive the invite, please register HERE

Can Exercise Help People with Dementia?

By Victoria S. Pelak, MD
Professor of Neurology and Ophthalmology
University of Colorado School of Medicine

It is now very clear that regular **exercise helps to lower the risk for dementia**. So, does this mean there is no controversy? Not exactly. Where the data have fallen short is whether exercise as treatment *after* someone develops dementia is effective. There have been some studies that show exercise can slow loss of cognitive function and loss of memory for those with dementia and other studies that show that exercise cannot slow memory loss and cognitive decline once dementia sets in. Let's start with the basics and define what is meant by dementia and what is meant by exercise.

First, the term **dementia** does not refer to a specific disease. Many different diseases can cause dementia, such as vascular disease of the brain (or multiple small strokes or one or more large strokes), Alzheimer's disease, or Lewy body dementia. As you know, PCA is also not a disease. It is a syndrome made up of a constellation of symptoms that are due to a degenerative disease of the brain. The disease that most commonly causes PCA is Alzheimer's disease, followed by Lewy Body Dementia. See the Colorado PCA support webpages for more information on what is PCA and what causes the PCA syndrome: https://medschool.cuanschutz.edu/pca/what-is-pca/what-is-pca

A person is diagnosed with dementia when the degree of cognitive impairment reaches a level that interferes with a person's ability to perform activities of daily living and live independently. Examples of activities of daily living include managing finances, working (if not retired), cooking or preparing food, grocery shopping, getting dressed, or bathing. With the diagnosis of PCA, sometimes it can be difficult to determine when the onset of dementia starts, since visual processing can influence many activities of daily living despite maintaining relatively good memory and judgment.

What the research does tell us about exercise for those with dementia, and this likely applies to PCA as well, is **that exercise improves mobility and muscle strength and can increase independence in many activities for those with dementia**. Although exercise as a treatment for slowing cognitive decline associated dementia is yet to be unequivocally proven effective, the physical benefits and gait stability related to exercise are critical for living a higher quality of life as dementia sets in.

Furthermore, **exercise has been shown to improve mood, depression, and anxiety in those living with dementia**. The benefits of mood are significant and can improve quality of life.

Is starting to exercise ever 'too little and too late'? Good news! Recent studies show that even a small amount of exercise after middle age can help. If you are not used to exercising, you can start with 5-10 minutes of stretching per day and work up to light weights to help with muscle and bone health. Then, you can start walking, even 5-10 minutes per day at first. It is recommended that you try to increase your movement and exercise slowly if you have not exercised before or have not exercised in many months or years. Eventually, you should work your way up to 150 minutes per week. Many people worry about the level of intensity and whether it is enough. Although data are being published on this topic nearly every month, recent studies show that simply increasing your heart rate to a mild degree while exercise might be all that is necessary. A good example is brisk walking or even housework that causes your heart rate to increase or causes you to break a sweat. As an important reminder, if you have a heart condition or other physical concerns, please discuss exercise with your primary care doctor to know how best to start exercising.

In summary, we now know that physical exercise can help decrease risk for dementia in people with normal cognition and in those with mild cognitive impairment. This is true even for small doses of exercise, and exercise is particularly helpful when you reach 150 minutes per week. Start slow if you do not exercise regularly. For those with dementia, the benefits of exercise include improved overall mobility, gait, and mood, although the benefits for slowing cognitive decline and memory loss is less clear.

Overall, given all the benefits of exercise that occur at any age or at any stage of brain health, it is clear that if we could bottle the benefits of exercise in a pill, everyone would want a prescription! **If you have a story about exercise that might inspire others or want to share your journey, we would love to hear from you. Please send us exercise stories that might inspire others to get up and get moving: COPCA@cuanschutz.edu**

New Research Associates Join the PCA Research Program at CU

Asher Mahmood, MSc

Lily Noteboom, BS

We are excited to announce that the PCA Research Program has two new research assistants who started in 2022. Asher Mahmood, MS began working at the University of Colorado in the Department of Neurology with Dr. Pelak in April 2022 and Lily Noteboom, BS started in October 2022. They are working with Dr. Pelak to understand the longitudinal course of PCA and the best methods for assessing changes with the future goal of finding the best outcome measures to use for clinical trials. The funds that sponsor research that Lily and Asher are engaged in are from a generous donation by the Hare Family and from donations by donors to the University of Colorado Alzheimer's and Cognition Center. Together with Dr. Pelak, they are hard at work analyzing data and planning future studies. To read more about this research, see the article in this newsletter "Accelerating PCA Research Toward Clinical Trials." In that article, you will learn how understanding changes over time and determining the best methods for assessing PCA will help bring PCA clinical trials closer to being realized. Meanwhile, we are excited to introduce our new team members. Both have critical skills and experience related to outcome measures, which will be important for our current and future work.

Introducing Asher Mahmood, MS

Asher joined the University of Colorado's Neurology Department as a research associate for PCA research with Dr. Pelak in March of 2022. He graduated from the University of Michigan-Dearborn with a Master of Science in Health Psychology and moved to Colorado to join the new PCA research team. He is pursuing a career focused on the impact of long-term, chronic conditions. Asher is excited to work in an underserved field and to help serve patients with PCA and their families navigate their daily lives. For his master's thesis, Asher investigated the validity of measures used to assess the psychology of individuals with chronic pain. He hopes to use these skills to better help understand different manifestations of PCA and strengthen the methods used to track PCA progression over time. Doing so will open the door for future clinical trials. Originally from Michigan, Asher enjoys exploring the outdoors, listening to podcasts, and reading a good book. Asher has led the efforts to manage our research database and preparing ongoing data for analyses, and we could not be happier to have him on board with us.

Introducing Lily Noteboom, B.S.

Lily joined the PCA research team in October 2022. She received her Bachelor of Science in Psychology with a concentration in Cognitive Neuroscience from the University of Denver (DU) this past June 2022. Before joining the University of Colorado Department of Neurology, she worked for nine months with a research team at DU that focused on concussion, primarily those experienced by athletes. While working with this group, she was a team lead for a Long-COVID-19 study that assessed COVID-19's lasting impacts using post-concussive symptom testing measures and submitted a manuscript for publication in late September 2022. Lily stated that "While I am new to PCA research, I have appreciated learning about the different ways PCA can present. I find our research interesting given that much of it is based on finding the best ways to better assess for the features of PCA in patients. I am very interested to see which assessments we can transition into an online format." Lily is referring to a goal of one of the projects she will be working on: making assessment tools widely available using online formats for visual stimuli for testing, which has important implications for early detection and clinical outcome assessments. We are excited to have Lily onboard.

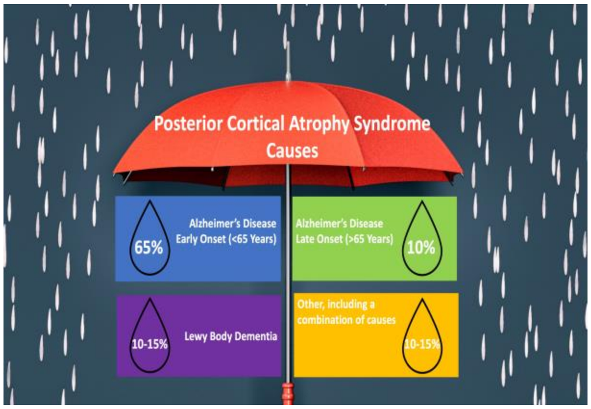
ACCELERATING PCA RESEARCH TOWARDS CLINICAL TRIALS

The PCA research team is hard at work to answer one of the most difficult questions patients and family members want to know: What do the next few years look like for me? We currently understand that PCA progresses to dementia, but there is very little data on how the symptoms and signs of PCA change over time after symptoms appear. Without answers to questions about change over time, patients and family members are left without knowing and with uncertainty about the future. Research at the University of Colorado and around the world is slow, but a gift by the Hare Family has allowed us to accelerate the pace of discovery.

Understanding how PCA progresses over time is not only important knowledge for patients and families, but data about progression is critical for treatment trials (i.e., clinical trials). We must understand how people change to know if an intervention, whether it be with a drug or with another type of treatment, is effective. Currently, the batteries or the assessments that are used to determine how a person with PCA changes are taken directly from Alzheimer's disease assessments. Many of you have pointed out that some of the assessments don't truly capture PCA progression or don't truly measure the important changes that take place over time. Dr. Pelak has been working with researchers throughout the United States and Europe to identify and recommend a starting place: standard measures that capture each element of impairment that might be present when a person is impacted by PCA. This work started in 2020 and was recently completed with a manuscript submission currently ongoing. A goal that is evolving from this project is to make the battery and assessments available online with easy access for any clinician, including optometrists, ophthalmologists, cognitive neurologists, and neuropsychologists. These assessments should help with early identification and future research will determine how well they perform to appropriately identify changes in visual perception, cognition, and function in those with PCA. We look forward to telling you more about this as the research evolves.

Common Causes for the PCA Syndrome

Figure by Asher Mahmood

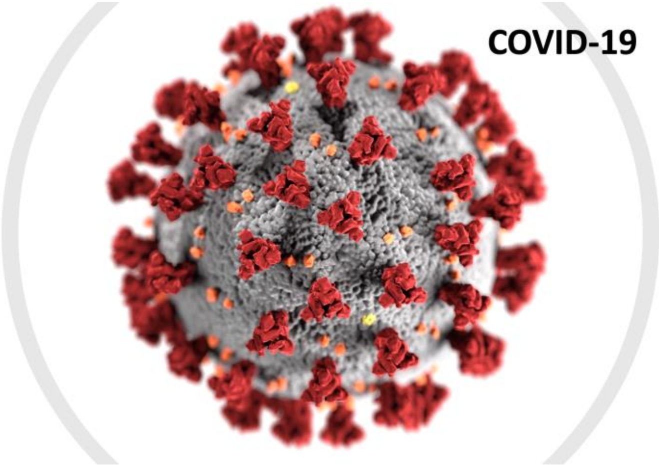


The PCA syndrome can be caused by several different diseases or a combination of disease. The figure above illustrates the most common diseases that result in the PCA. As one can see, Alzheimer's disease is the most common cause of PCA and includes up to 75% of people with PCA. If symptoms begin before age 65 years, we consider this Early Onset Alzheimer's disease or EOAD. The majority of those with PCA have EOAD with far fewer having Late Onset AD or other diseases such as Lewy Body Dementia or other diseases that are very uncommon. In some instances, a person with PCA has a combination of Alzheimer's disease and Lewy Body Dementia. The underlying cause will be important for future treatments since treatments for one disease might not impact another disease. Symptoms can start the same, but progress differently, depending on the cause.

Return of the PCA Summer Research Intern in 2022

This summer, Dr. Pelak welcomed the 2022 Summer Intern for PCA Research, after two long years without the ability to do so because of the rules in place during the COVID-19 pandemic. The Summer 2022 Research Intern chosen was Kathryn Abe-Ridgway, BA. She is currently a second-year medical student at the University of Colorado School of Medicine, and she worked with our PCA research team in August 2022 to analyze longitudinal data from the Colorado BioPCA Registry study. In addition, she helped to analyze available published data regarding longitudinal changes in PCA. It was a great experience to have Kate with us during her summer break from CU School of Medicine, and she did terrific work. Kate has a curious and scientific mind, and she learned a lot about PCA during her time with us. The work that was done this summer with Kate led to a manuscript that was accepted to *Current Neurology and Neuroscience Reports*. The manuscript was authored by Dr. Pelak, Kate, and Asher (see article on our new research associates to learn more about Asher), and it was focused on a review of longitudinal PCA data available in the literature. Dr. Pelak stated that “We learned a lot by analyzing the literature and summarizing what is known and reporting where there are substantial gaps in our understanding. There is a lot of work to be done to understand changes that occur in PCA over time and to determine what the best tools are to measure these changes. We must work diligently to understand this before we can move closer to a clinical trial for PCA.” We thank Kate for her valuable contribution, and we wish the best to her in the future. To learn more about Kate and her experience this summer, we included her bio and a message to the support group from Kate.

A message from Kate: I am from Pasadena, California and went to UC Davis for undergrad where I discovered a love for community gardening and college radio. I then moved to Colorado after graduating in 2019. Prior to medical school I worked in a psychology lab for 2 years at CU Boulder and developed an interest in neuroscience and the sensory systems. So far in my clinical year (in medical school), I have enjoyed my medicine and surgery rotations equally and I would love to work in a specialty that combines elements of both. Over this summer I loved getting to dive deep into the fields of neurology and vision and learn about Posterior Cortical Atrophy. I gained an appreciation for how difficult it is to characterize a relatively newly discovered syndrome that is rare. There is so much that is unknown about PCA, and I am excited to see the research field and body of knowledge grow. This internship and the opportunity to participate in research has had a big impact on my medical school journey. After seeing how much clinical research and teaching enriches patient care, I am eager to incorporate research into my career. I’m grateful to Dr. Pelak for the opportunity to work closely with her and admire her work to both further understanding of and increase research funding for PCA patients. Her patients are lucky to have such a fierce advocate. And thank you to the generous donors who made this internship possible!



The COVID-19 Pandemic and Cognitive Impairment: Infection and Beyond

By Lily Noteboom and Dr. Pelak

Since the emergence of the coronavirus disease (COVID-19) pandemic due to SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) in early 2020, there have been many impacts on society that go beyond the illness associated with infection. The world went into lockdowns of various degrees that were necessary to prevent death and limit the healthcare crisis imposed by the pandemic. It has been shown that these drastic measures decreased spread of the virus and deaths from infection before the development of COVID-19 vaccinations allowed a slow return to a more ‘normal’ existence. However, the social isolation and the decreased access to basic healthcare that occurred during the early part of the pandemic were among the burdens that persons with dementia and their care partners felt deeply. Daily activities had to be adjusted or diminished and medical care was often delayed. For those with dementia, the impact of these changes are still being felt and investigated. We are continuing to learn more about the adverse impacts of the pandemic. Although the pandemic influences upon those with Posterior Cortical Atrophy have not been systematically studied, at CU School of Medicine we note many family members of those with PCA reported more rapid decline in function had occurred while in quarantine for those in assisted living facilities, and we saw an increase in reports of behavioral changes in those with major disruptions to daily routines or decreased interactions with friends and family members outside of the home. Based on our observations, we believe that data gathered regarding the COVID-19 pandemic and cognitive impairment, or dementia, are likely to apply equally to those with PCA.

At Higher Risk Older adults with cognitive impairment or dementia remain at higher risk for SARS-CoV-2 infection, and once infected, they have a higher rate of more severe illness and COVID-19 related mortality. Regulations and restrictions that are meant to prevent infection or limit exposure to SARS-CoV-2 can be difficult for those with cognitive impairment to understand or fully comply with, such as wearing a mask or maintaining proper social distancing. These issues are believed to lead to increased infection rates. Additionally, many of the risk factors associated with more severe illness from COVID-19 are shared by those with dementia, including older age, cardiovascular disease, hypertension, and diabetes. All of these factors lead to both greater risk for infection and worse outcomes after infection.

Beyond risks associated with direct infection, social isolation imposed by the pandemic has been shown to increase the development or exacerbation of mood and behavioral disturbances in those with cognitive impairment or dementia. Data reveal that approximately 60% of those with dementia experienced mood and behavioral changes associated with the pandemic during quarantine, which in turn caused additional distress for care partners and family members. In another study, it was noted that 64.7% of caregivers experienced increased “physical burden” and 80% experienced “psychological burden” during this time. Self-care for care partners has become an essential part of caregiving, and the pandemic exposed problems that can occur when this is not easy to do. Since the easing of restrictions that came with effective vaccines, we have seen many patients with PCA move to be closer to friends and family to allow for more opportunities for caregiver self-care, increased socializing, and shared caregiving.

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COVID-19 Vaccinations The development and rapid dissemination of vaccines against COVID-19 was unprecedented and resulted in many fold fewer deaths. According to the Center for Disease Control, as of November 16, 2022, over 650 million doses of COVID-19 vaccines have been administered safely in the United States, and according to the Bloomberg Vaccine Tracker, by October 2022 approximately 12.7 billion vaccine doses have been given worldwide. With billions of people receiving vaccinations safely, it is now abundantly evident that the benefits of vaccination against COVID-19 outweigh the very rare vaccine side effects that can occur. Recent data show that vaccines are more effective at preventing severe disease than having had a prior course of COVID-19. Thus, one of the greatest protections against COVID-19 and the adverse effects of the pandemic is vaccination and staying up-to-date with vaccine boosters.

Early data also reveal that long-COVID is less likely to occur in those who have been vaccinated, and this is critically important since long-COVID might be as likely to occur in those with only mild infection compared to those with severe symptoms. Some studies show that those seeking treatment for long-COVID were more likely to have mild symptoms, and the reasons for this finding are unknown. Long-COVID symptoms include brain fog, memory impairment, fatigue, autonomic nervous system dysfunction, and sleep disturbances. Each of these have the potential to contribute to faster cognitive decline. Staying protected and avoiding COVID-19 remains important today.

Does SARS-COV-2 Infection Worsen Cognition or Lead to Dementia? Medical researchers will be attempting to answer this question for years to come, but some data that is available now show that infection can diminish cognitive capacity even after a mild COVID-19 course and particularly after severe illness. According to Vanderbilt University Medical Center, about 55% of people who were treated for COVID-19 in intensive care units around the world developed delirium. Delirium is the abrupt onset of disorientation and confusion that can be associated with visual or auditory hallucinations (seeing or hearing things that are not experienced by others). Roughly 70% of people with symptoms of delirium in the setting of COVID-19 eventually recover, but worrisome data from a study published in 2020 that collected data from 23 different studies found that people with COVID-19 were 2.3 times more likely to develop symptoms of dementia following delirium during a hospital stay. It is possible or even probable that those who developed dementia after delirium were harboring pre-dementia disease, such as pre-symptomatic Alzheimer’s disease, and the disease onset was hastened by COVID-19 and its impact on the brain. This is not yet known, however.

A more recent study published in 2022 analyzed data from over 13,000 people with COVID-19 and revealed that 22% of people exhibited ongoing cognitive impairment greater than 12 weeks after the diagnosis of COVID-19. Thus, while delirium may be short term during the infection, cognitive dysfunction can be a longer-term consequence, but exactly how long and whether the development of dementia increases in the future is unknown.

One theory for persistent cognitive impairment is that inflammation induced by the virus crosses into the brain due to vascular “leakage” that is prominent with SARS-CoV-2 infection. Further damage of blood vessels in the brain related to infection and inflammation can also lead to small or large vessel occlusions resulting in both mini-strokes and major strokes. Those with more severe illness and hospitalization and those requiring intensive care unit stays are at an even higher risk for memory loss and fatigue, anxiety, depression, and sleep disturbances, which can each impact cognitive function. Even those without delirium or hospitalization can experience memory dysfunction and slowing of cognition, often referred to as brain fog, following COVID-19.

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Future Outlook We will one day have a better understanding of the impact of the COVID-19 pandemic upon those with cognitive impairment and dementia and upon those with healthy cognitive aging before the pandemic. For those who experienced infections and were already suffering from dementia or mild cognitive impairment, it is now clear that outcomes were far worse than they were for older adults with healthy cognitive aging at the time of infection.

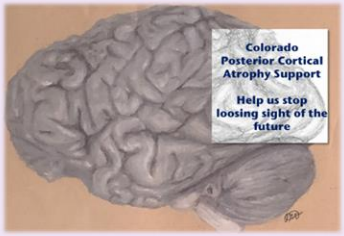
Understanding how COVID-19 might speed up cognitive decline or result in cognitive decline will be the focus of ongoing studies for many decades to come and answers might one day help us understand how infections and the immune system contribute to dementing diseases. Other areas being actively investigated include how social isolation and delayed medical care influenced those with cognitive impairment and dementia and their care partners. Although the lockdown measures were shown to help prevent an even greater public health crisis than what was experienced, these tactics have also been shown to have negative effects, particularly upon those with cognitive impairment. We need to learn more about these outcomes so that new approaches can be implemented with future pandemics or a future exacerbation of the current COVID-19 pandemic.

Lastly, an encouraging development related to the pandemic is the rapid advances made in vaccine development and production and the successful administration of billions of doses of a safe vaccine. Data revealing that COVID-19 vaccinations not only have a significant impact on the severity of the illness related to COVID-19 but could decrease the occurrence of persistent and lingering symptoms that impact cognitive function is truly remarkable. With the advent of COVID-19 vaccinations, we have also been able to end social isolation and provide timely medical care for those with debilitating cognitive diseases. The vaccination breakthrough gives hope for a brighter future.

TIPS FOR LIVING WITH PCA

Did you know we have gathered tips from people with PCA and their families and care partners? Over the years we have learned what works to make the environment a bit easier to negotiate if you have PCA. Many of these tips and techniques are rooted in how the brain processes visual information and the changes that take place when PCA occurs. **See our webpages** for the many options that you can try. Everyone with PCA is different. What works for one person might not work for another. One tip for better living that seems to work for many, however, is to systematically simplify the environment in the home. In a word: declutter. For many reasons, some of which are becoming clearer, the brain under the influence of PCA cannot focus attention or interpret information under crowded conditions. For instance, if you have PCA, it is easier to read when letters and words have more space between them. By adding space, what you are looking at is less “crowded” and less “cluttered”. Below is an example you can try. See how fast it is to list the first string of letters and number compared to the second.

A 3 2 6 L T 9
B69R74



Have you visited the Colorado PCA Support webpages? If not, you can find videos, frequently asked questions, tips for compensating for visual brain function, and much more. To learn more, go to: https://medschool.cuanschutz.edu/pca