

# Colorado PCA Support

## QUARTERLY NEWSLETTER

Colorado Posterior Cortical  
Atrophy Support



Help us stop losing sight  
of the future



### Science Meetings International Meetings

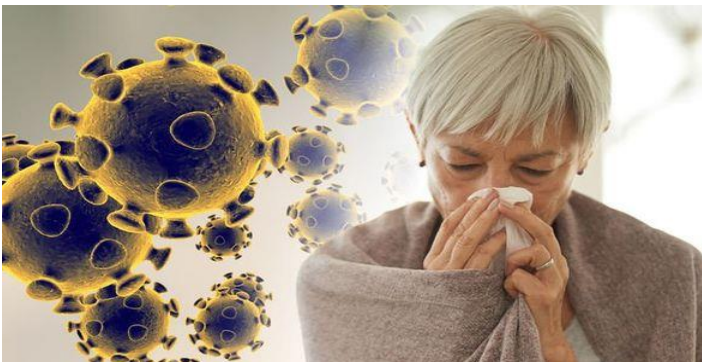
See below for news from Dr. Pelak on the North American Neuro-ophthalmology 2020 Meeting that occurred in March 2020. Learn more about the 2020 Alzheimer's Association International Conference Meeting that is scheduled to take place in July in the Netherlands.



To inform and help you stay healthy during the COVID-19 Pandemic, see our reminder list and Frequently Asked Questions page. A section on coping with anxiety and stress associated with COVID-19 was written with PCA in mind.

### Colorado PCA Support Group Webinar 10–11am May 20, 2020

Our next meeting will take place via **WEBINAR** on the topic of **RESILIENCE** on Wednesday, May 20, 2020 from 10 am - 11 am. Please sign up [HERE](#) and you will receive an email with a link to the webinar. For more information on the speaker and topic, **SEE BELOW**.



### CORONAVIRUS DISEASE-COVID-19

If you have any questions regarding the Coronal Virus Disease (COVID-19) you can obtain additional information at [www.cdc.gov/coronavirus/2019-ncov/about/index.html](http://www.cdc.gov/coronavirus/2019-ncov/about/index.html)

## PCA Support Group Speaker

Our next PCA Support Group meeting will be May 20, 2020 at 10 am. We are planning this to occur as a WEBINAR. Our guest speaker will be Jill Lorentz, who will speak about "*Emotional Absolutes for Those Living with Dementia and for Those Caring for Persons Living with Dementia*". Ms. Lorentz is the President of Summit Resilience Training for Dementia Education for Caregivers. Her webpages are here: <https://summitresiliencetraining.com/>

[www.coloradopcasupport.org](http://www.coloradopcasupport.org)

Jill Lorentz, President of Summit Resilience Training



### International Meetings

#### UPDATES FROM DR. PELAK:

**NANOS:** The 2020 North American Neuro-ophthalmology Society (NANOS) Annual Meeting took place in March 7-12, 2020 before the COVID-19 Pandemic resulted in conference cancellation and travel limitations. NANOS is a society for neuro-ophthalmologists, who are experts in caring for patients with visual issues stemming from the nervous system, and neuro-ophthalmology is one of the two areas of subspecialty that I practice within. To learn more about the field, go to: <https://www.nanosweb.org/i4a/pages/index.cfm?pageid=1>.

Each year the NANOS meeting has clinical, educational, and scientific sessions. This year there were clinical sessions that included PCA-related conditions and PCA. There is a growing awareness of PCA in many fields and neuro-ophthalmology is leading efforts to raise awareness of PCA and brain-related vision problems.



**AAIC:** The 2020 Alzheimer's Association International Conference is scheduled for July 26-30, 2020 in Amsterdam. It has not been cancelled as of April 4, 2020. In a recent year, over 6000 scientists from over 68 countries attended the meeting and there were 3,400 scientific presentations. The Alzheimer's Association is considering COVID-19 Pandemic and risks associated with holding such a large, international meeting. Based on the current status of the pandemic, from my perspective, it is unlikely that it will take place, unfortunately.

## COVID-19 PANDEMIC Stop the spread!



- Practice social distancing
- Wash your hands with soap and warm water for 20 secs
- Avoid touching your face, mouth, and nose
- Keep frequently touched surfaces clean with household cleaners or disinfectants
- If you are sick, isolate from others and call your primary care physician to determine the best course of action if you develop cough, fever, or flu-like symptoms
- For shortness of breath, go to the emergency room

**SEE FAQ SECTION BELOW**

## COVID-19 PANDEMIC: FREQUENTLY ASKED QUESTIONS

For questions and help related to caregiving in these times, reach out to the Alzheimer's Association helpline: CALL 800.272.3900 AT ANY TIME 24 HOURS/DAY.

### Who is at risk for severe complications of COVID-19?

- Older age (65 years and older)
- People with diabetes, heart disease, lung disease, liver disease, obesity, kidney disease, and those receiving treatment for cancer
- Smokers can have lung disease without knowing it, and it is never too late to quit

### How do I stay healthy and avoid COVID-19?

- Social distancing is the most important thing you can do to prevent COVID-19
- Do not babysit or visit family members, especially if you are at high risk
- Staying at home is important, but if someone is sick at home, that person needs to be isolated from others with their own bathroom and bedroom, if at all possible

### Are there medications I can take to prevent COVID-19?

- There are no medications that prevent COVID-19
- Worldwide, there are over 60 medications and other treatments that are being used compassionately or in clinic trials to treat complications of COVID-19
- Do not rely on social to learn facts about treatments
- Visit the CDC online regularly for updates on all aspects of the COVID-19 Pandemic: <https://www.cdc.gov/coronavirus/2019-ncov/index.html> and for specific information regarding treatments, including hydroxychloroquine and chloroquine, see: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/therapeutic-options.html>

### If I think I have COVID-19 Infection, what should I do?

- For cough, fever, flu-like symptoms, you should call your primary care doctor's office to discuss
- If you have a fever that is difficult to control or shortness of breath, particularly with cough or fever, you should not wait to review this by phone with your doctor. You should go to the emergency room (have someone call to let them know you are coming) or call 911
- Do not go to the emergency room to get tested (there are testing guidelines in place that change frequently and you risk getting infected by going to the emergency room or infecting others when you might not qualify for a test)
- See <https://covid19.colorado.gov/> for additional information and local resources

### How do I get tested for COVID-19?

- In Colorado, you must have an order from your doctor
- Do not go to the emergency room to get tested
- To learn more details about testing, go to: <https://covid19.colorado.gov/testing>

## COVID-19 PANDEMIC: Taking Care of Your Mental Health

It is normal to **feel the impact of the COVID-19 Pandemic** by experiencing an increase in anxiety and a decrease in cognitive functions due to the anxiety. This is especially true for those with PCA. So, what should you do when you are feeling anxious and need to find relief? Find an activity that gets your mind off of the news - create videos, record a poem, or watch a TED talk.

When anxiety starts, **talk to others**. Talking to people about your fears and anxiety will help, but if you are not ready to do that, then simply talk about anything: ask about their favorite vacation, or their plans for the next one, or their favorite recipe. Learn to use FaceTime, Skype, or other virtual communication applications so they can see you, even if it is difficult to see them. Call and ask a friend or family member to help you or your care partner set up an application on your computer or smart phone for video calling. It will help you get ready for Webinars.

Maintain your fitness with **exercise**. If you are able, take a short walk around the block. Indoors, you can come up with new ways of getting active. There are many free classes that are being offered online right now. Search Google using terms such as *free exercise classes*.

Take time to **learn meditation or other techniques** to relax. Headspace is a popular application to help with relaxation. Click here: <https://www.headspace.com/meditation/meditation-for-beginners>

Find a way to **help a cause** you want to support. Donate to the [Alzheimer's Association](#), [Colorado PCA Support](#), or the [American Red Cross](#). Every dollar counts. Make a video about your life with PCA and we might post it to our site to help raise awareness. There are so many things you can do to help. Call an organization and ask how you can. Like John Elway, leave an encouraging message for UCHHealth employees: <https://www.uchealth.org/extraordinary/thankyou/>, who could use words of encouragement during this time. Call and check in on someone who lives alone. We are all in this together and you never know how much your words will help.

For ideas to take your mind off the pandemic, The Alzheimer's Association provides some great ideas [click here](#).

### THE COLORADO PCA SUPPORT FEBRUARY 2020 WEBINAR IS NOW AVAILABLE TO VIEW ONLINE ON OUR WEBPAGES!

On February 19, 2020 we held our first Colorado PCA Support Webinar to answer questions from patients, family, and care partners. Given the positive feedback from registered attendants, including people from several states, the UK, and Israel, we are planning a future Q&A Webinar. Stay tuned for more information. A link to the video of the February Webinar can be found on our webpages and here: <https://www.youtube.com/watch?v=ldkzkxsDPqk&feature=youtu.be>

#### **ADVERTISEMENT from Our *PRIOR* Free Webinar on Posterior Cortical Atrophy (PCA)**

January 22, 2020

1:30 to 2:00 Mountain Time

11:30 to 12 noon Eastern Standard Time



Do you have questions about Posterior Cortical Atrophy? For instance, how is PCA related to Alzheimer's Disease or Lewy Body Dementia? Submit your questions and tune in to the Webinar to hear responses to your questions by Dr. Victoria Pelak.  
Sponsored by generous donors of the *Brain and Vision Fund* at the University of Colorado