

Colorado PCA Support

Annual Update January 2019

The New Year is once again upon us. As we begin 2019, we are reminded that there have been difficult times for members of our community. Posterior Cortical Atrophy never relents and everyday it challenges us to continue our mission to improve the lives of those affected by PCA. Below we list just a few of the benefits that your time and donations have had on PCA support, research, and awareness.

- First, our **PCA support group was in the news!** One of our members, Mr. Robert Yetz, is featured in a CBS4 news story with an interview by CBS4 anchor Kathy Walsh. You can view the story on the following pages while it is still available: <https://denver.cbslocal.com/2018/10/24/rare-form-alzheimers-affects-eyes-see/>. In addition, a journalist with the University of Colorado Healthcare newsletter picked up the story and went further in depth to learn more about Mr. Yetz and his care partner, Barbara Hubbard, in this heartwarming story found here: <https://www.uchealth.org/today/2018/11/27/a-brain-disease-that-betrays-the-eyes/>. Both stories have had a very positive impact on PCA awareness.
- Secondly, we have been able to use your generous donations to **enhance our support group meetings** with lunch or breakfast and speakers throughout the past year. We will continue to do so with available funds, and please let us know if you have any ideas or topics that you would like to see presented.
- Next, our center's **research data** collection is being finalized for two studies, and a third study that focuses on initial symptoms of PCA, worked on with collaborators, is in the final stages of preparation for publication. Stay tuned in the next year for summaries of our research findings.
- Finally, we have **revamped our PCA webpages** and this will allow us to provide updates and information using an easy-to-read format. Please check out our new pages at the same address: <http://www.coloradopcasupport.org/>

We want to remind you of the opportunities our **Neuro-Palliative Care Clinic** can offer to patients, families, and caregivers/care partners, including: Advance Care Planning, Complex Symptom Management, Caregiver Support, Spiritual Support, Psychological Issues, Social/Family Issues, and Care Transitions (i.e. moving to independent and assisted living facilities). This type of support cannot be readily provided with a typical doctor's visit. We encourage everyone to schedule time with this invaluable resource in University of Colorado Neurosciences Clinic.

We hope that you will share this information with those who have supported you throughout the year. Finally, we hope friends and family will continue to support our efforts with contributions to our brain and vision fund. Whether the donation is \$5 or \$500, it benefits our cause to support those with PCA and to fund our research efforts. You can give on our PCA support webpages or directly at this address: <https://giving.cu.edu/fund/brain-and-vision-fund>.

In hope for a brighter future,

Dr. Victoria S. Pelak and Jerri Lusk