

Campaign for 50K in 2020



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November 15, 2019

Dear All,

Many of us have very special holiday traditions, and this letter is an annual tradition to update you on the progress we have made in PCA research, PCA support, and PCA awareness.

First, I want to acknowledge that there are many of you feeling discouraged. I am too. There have been over 400 treatment trials for Alzheimer's disease that have all failed! There was only one treatment trial for PCA that has been completed and this involved very few people over a very short period of time and showed that donepezil (brand name Aricept) does not change memory and thinking after 12 weeks of use. PCA can also be caused by Lewy Body Dementia and, just like Alzheimer's disease, there are no treatments that halt or slow Lewy Body Dementia. Writing this is disheartening, and living with this reality is devastating! Science is moving too slowly, and research in PCA is done by too few scientists. I am dedicated to changing this and my mission is to accelerate research to improve our understanding and treatment of PCA. You too can make a difference.

To jump start this mission, we have increased our fund-raising goal to \$50,000 by the end of 2020. Since 20/20 stands for 'perfect vision', it is only fitting that we reach this goal by 2020. We will use this money for a full-time research assistant and to continue our Summer Internship Program for PCA Research in order to help us launch a large, international study of PCA in the future. See the handout enclosed to learn more.

In closing, during this season when we reflect on the many things for which we are grateful and continue to search for hope, we are offering that hope for the future and ask you to join our campaign. Ask family and friends to join our campaign as well. Share with them the **Campaign for \$50K in 2020!** To donate, go to <http://www.coloradopcasupport.org/> or call us at 303 724 2184 or email us at pca@ucdenver.edu and we will help you with your donation. From \$10,000 gifts to \$5 gifts, every dollar leads to forward momentum. Attached you will find a summary of our progress toward improving the lives of people touched by PCA.

In hope for a brighter future,



Dr. Victoria S. Pelak
Professor of Neurology and Ophthalmology
University of Colorado School of Medicine

The 2019 Year in Review: Colorado PCA Research and Awareness Events and Successes

<http://www.coloradopcasupport.org/> By Jerri Lusk, Administrative Director PCA Support Group

- In June 2019, our Colorado Posterior Cortical Atrophy BioBank and Registry study was approved. The aim of the study is to understand the clinical changes that occur in PCA by analyzing clinical data, brain imaging data, and biological samples from a large number of individuals. Up to 150 people from our area will participate in the study. If you have not yet signed up for this study, contact us to learn more at 303 724 2184 or pca@ucdenver.edu.
- In July 2019 we launched our *Summer Internship Program for PCA Research* and we received a large number of spectacular applications. We awarded the internship to two CU medical students, Stephanie Serva and Vishal Krishnan. They attended a support group meeting, visited with patients outside of clinics, and collected and analyzed data for the Colorado PCA BioBank and Registry study. They submitted an abstract to the *International Neuropsychological Society 2020 Annual Meeting* titled “*Patient Characteristics from the Colorado Posterior Cortical Atrophy BioRegistry*” and we just learned that their abstract has been accepted. They will present their findings in early 2020.
- Dr. Pelak presented a scientific abstract on PCA at the Alzheimer’s Association International Conference in July 2019, where she also presented plans for the future development of an International PCA BioBank Consortium. The planning committee for the International PCA BioBank Consortium met in person twice during the past year and there are over 20 researchers interested in participating, including scientists from institutions throughout the United States, and in Canada and Europe. We will bring you more news as the plans unfold.
- We had four successful PCA Support Group meetings this past year (and our final meeting of the year will be on December 4, 2019). Our speakers included CU Neurology Faculty: Peter Pressman, MD; Samantha Holden, MD; Christina Vaughan, MD; and Brice McConnell, MD, PhD. If you missed out on these guest speakers, you can view them by going to our webpages (<http://www.coloradopcasupport.org/discussions>). Topics included Lewy Body Dementia, Sleep and Dementia, and the Neurology Palliative Care Clinic (to signify ‘relief from suffering’ and not ‘end of life’).
- Our ties to the Neurology Palliative Care Clinic have grown and this clinic offers people with PCA and their families and care partners the following: Advance Care Planning, Complex Symptom Management, Caregiver Support, Spiritual Support, Psychological Support, Social/Family Issue Support, and Care Transitions (i.e. moving to independent and assisted living facilities). This type of support is not provided with a typical doctor’s visit. Thus, we encourage everyone to schedule time with this invaluable resource in University of Colorado Neurosciences Clinic. For a referral, please call Dr. Pelak’s office to request a referral or visit here to learn more: www.ucdenver.edu/academics/colleges/medicalschool/departments/neurology/clinical/Pages/Neuropalliative-Care-Clinic.aspx
- During the past year, we raised awareness about PCA at the Annual Alzheimer Education Conference held by the Colorado Chapter of the Alzheimer’s Association. Two of our PCA Support Group members, Bob Yetz and Bill Burns, represented the PCA Support Group with Jerri Lusk at a vendor table and enjoyed speaking to those who stopped by to learn more.
- Mr. Bob Yetz was also featured in the UCHealth Today newsletter (with many subscribers across Colorado) regarding his experience with PCA. This was preceded by an interview that aired in a local CBS Denver news story where Bob, and his care partner Barbara, along with Dr. Pelak, introduced PCA and what it is like to live with the disorder on a daily basis.