Connecting Around the PC World

PCers Jennifer Hart and Natalie Kendrick met through the Pachyonychia Congenita Patient Chat, a private Facebook group where those with PC share thoughts and tips about living with PC. https://www.facebook.com/groups/pachyonychia/

Jennifer and Natalie discovered they only live five miles away from one another in the UK and arranged to meet in person. As they talked, they discussed ways to increase the profile of PC Project in the UK and the importance of everyone with PC joining the Registry.

These women demonstrate the power of PC Project growing globally. If you want to be in touch with PCers who live near you, please contact PC Project and request we share your contact information with PC patients in your part of the world.

PC Project at the AADA Annual Legislative Conference

PC Parents Barbara Feinstein and Aaron Klein (their daughter Audrey is K-17) represented PC Project at the American Academy of Dermatology’s Annual Legislative Conference, held September 8-10 in Washington, DC. The meeting brought together more than 200 dermatologists and representatives of patient advocacy organizations to lobby Congress on issues affecting dermatology and patients. In addition to raising awareness of pachyonychia congenita among Members of Congress, doctors and patient groups, Barbara and Aaron also pressed legislators, including Representative Jamie Raskin (D-MD) [See photo below] to prioritize funding for rare diseases.

Shopping For PC

As the holiday shopping season approaches, don’t forget that when you use AmazonSmile to make your purchases, you can choose to support Pachyonychia Congenita Fund and Amazon will give PC Project a small percentage. Every bit counts. Thank you for supporting Pachyonychia Congenita Fund by shopping smile.amazon.com or smile.amazon.co.uk

Another Way to “Donate”

We continue to collect PC teeth. The National Institute of Health has an on-going study on PC teeth. If your baby teeth come out or you are having any teeth or molars extracted, please save them and send them to PC Project. This month’s tooth donor award goes to Caidan Martinez, a 7 year old PCer, who donated two of his baby teeth this month. Thank you Caidan!
PC Project Board of Trustees Welcomes New Board Member Kay Dee Holmes

Kay Dee was reared in Idaho Falls, Idaho and received an Associate’s degree from BYU-Idaho. But, her schooling took her to the other two “corners” of the state of Idaho. She received a Bachelor’s Degree in history from Boise State University and a law degree from University of Idaho. She is licensed to practice law in Idaho. Currently, Kay Dee works for the University of Idaho negotiating contracts and ensuring compliance with state and federal law. But, she is especially passionate about drafting contracts in plain English and eliminating legalese. In her free time she enjoys being outdoors, road trips, reading, studying history, and binge watching a good TV show or watching movies (when she can find one she enjoys!).

PC Awareness

Supporting PC Project comes in many forms. PC Patient, Candida Torres DeJesus taking PC awareness to a whole new level (see photo).
“Do I get paid for being in the study?”
Yes, you are paid for your time and effort. The amount is up to $1,200 if all visits and assessments are completed.

“How can I participate if I can’t take time off of work to travel to clinic visits?”
At the end of September 2019, a new site opened that can see VALO patients on the weekends. If you would like to participate at this site, you can contact PC Project.

“Does the study provide financial reimbursement for babysitting?”
Yes, the study provides reimbursement for respite care (care for children, spouse, seniors, animals, etc.). You will have to provide receipts or documentation.

“The nearest site is 3 hours away, too short to fly. What if I can’t drive, don’t want to drive and/or don’t have someone to drive me?”
The study provides transportation to and from the clinical site for you and a companion. In this case, a car and driver would be provided to you to assist with the round trip. The study also provides financial support for transportation (train, bus, gas mileage, tolls, airfare), lodging and other costs incurred as a result of study participation.

“How can I find out if I might be taking a medication that I can’t take during the study?”
First, don’t stop any medications that have previously been approved by your doctor. If you are interested in participating, please contact PC Project so they can connect you with a clinical trial clinician that can answer your questions to see if you are a candidate for the study.

“When will study enrollment close?”
Study enrollment may close as early as the end of 2019...but we need more patients! Please complete the short form at https://www.surveygizmo.com/s3/4854812/Phase2-3, if you are interested in participating to get started.

“What if the study drug works for me during the study, can I still take it after I finish the study?”
An extension study will be opening at the beginning of 2020, which will allow any patient that received study drug in the VALO study, and the patient and clinician believed helped the patient, to continue to use experimental PTX-022 (QTORIN™ topical rapamycin). The study drug will be provided at no cost to the patient.
Do you know someone who has PC? A family member or friend?

Are they 18 years or older?

Are they interested in helping to test a potential first treatment for PC?

We need your help to inform your friends and family about the opportunity to take part in our VALO clinical trial and help us to treat PC in the future. Participation is voluntary.

Please invite your family member or friend to sign up for the study here: https://www.surveygizmo.com/s3/4854812/Phase2-3

Invite your family member or friend to contact PC Project at 801-987-8758 or info@pachyonychia.org with questions or to learn more.
Seeking Participants for Pachyonychia Congenита Clinical Research Trial

If you or someone you know has Pachyonychia Congenита (PC), you may be interested in participating in a Phase2/3 clinical research trial for an experimental therapy that is applied to the soles of your feet.

Some of the requirements for participation include:

- Must be able to travel to sites in the United States. Travel may include driving and flying.
- Must be at least 18 years of age or older
- Have a clinical diagnosis of PC, genetically confirmed to involve any of three keratin genes KRT6A, KRT6B, or KRT16
  - If you have not been genetically tested, or if you do not have a copy of your genetic testing report, please contact PC Project at study@pachyonychia.org for more information about genetic testing.
  
  NOTE: If you know your mutation because a family member was tested, you will need to do a confirming test through PC Project, so you will have your own report.
- Have not participated in a clinical research study in the past sixty days
- On a daily basis during the study, wear an activity monitor and answer questions on a smartphone-based app.

Participants must be, in the opinion of the study doctor, able to understand the study, cooperate with the study procedures and willing to return to the clinic for all of the required visits. Your participation is voluntary.

If you qualify for study participation, you will be compensated for your time and your travel expenses to and from the clinic for you and a companion will be covered.

You can find more information about the study and participating sites on www.clinicaltrials.gov and www.valostudy.org.

If you are interested in participating, you can either:

- call a participating site directly, or
- email PC Project at study@pachyonychia.org