2020 France Patient Support Meeting

The European Patient Support Meeting (PSM) will be held in Roissy, France (near Paris), June 4-6, 2020. This is the only PSM to be held in 2020. (The 2021 meeting will be in the United States, location to be determined.) The France meeting will be held in English and French with translation. Reduced fees apply before April 1. Please register as soon as possible at pachyonychia.org/2020psm/

Many thanks to Le Coeur Au Pied for their help and support in organizing and planning this meeting with PC Project staff.

VALO Study Update

Do you know some treatments for diseases never get approved because there aren’t enough patients for the required clinical trails?

This is not the case for the PC patient community! The Palvella team has continually been impressed by the responsiveness of PC patients who have been willing to try this topical gel on behalf of PC patients worldwide.

This primary study will soon close enrollment. If you are interested in participating in the study, especially if you have already completed genetic testing and know your mutation, please indicate your interest immediately at surveygizmo.com/s3/4854812/Phase2-3 or Pachyonychia.org/valo/

A Letter About the Clinical Trial from a Mother & Wife

Dear participants of the current clinical trial and those who are eligible to participate in the trial but haven’t yet enrolled,

First off, this is a letter of gratitude. Thank you from the top to the bottom of my heart to all those PC patients who are giving up their time to participate in the VALO trial. As I said goodnight to my 12 year old son this week, after a particularly hard and painful day on his PC feet, he asked me if there would ever be a cure. As you all probably know, seeing someone we love in so much pain and being unable to help, is one of the hardest things to have to experience. It’s awful!

However, that night, I was able to explain to him how PC Project was recruiting patients into a study trying out a new treatment. When he asked when the results would be known, I explained not for a while as the study still needs people with PC to sign up and participate. Immediately he said he’d do it. Of course, he can’t as he’s too young, but as we also live in the UK, neither my husband nor any other PC sufferers from around the world can enrol. The trial is only open to those of you in the US and Canada.

In all the years of knowing about PC Project, I think this trial is the closest we’ve ever been to having a chance of finding something that may stop the pain. I ask any of you who are eligible and are considering, to please go for it! To do it on behalf of us who can’t and to do it for the future generations! Yes, being involved in research can be scary and takes time, but your help is desperately needed to understand what works and what doesn’t. Data from studies like these will be key to get companies to help us!
So, as we watch for news of the trial anxiously from across the pond and from the eyes of someone who is too young to participate, we want to thank all of you who have taken the leap and gotten involved. To those that are considering being involved, we encourage you, and most of all, thank you to PC Project for continually driving forward in the search for a way to stop the pain.

Sincerely,
Julie Peconi, wife & mother of two PCers

NEW DATA ABOUT PC

Two issues many PC patients deal with that aren’t typically associated with PC are deep itching and neurovascular-like structures (as seen in the below photos) in the calluses.

As new patients join the registry and share their experiences, PC Project is ever-learning about PC and how it affects patients.

In October 2019, PC Project surveyed its genetically confirmed patient community with an IRB approved registry addendum. With 350 responses, 69% of patients reported they experience deep itching, an itch that is under the calluses that is difficult to reach.

Furthermore, 62% of patients have neurovascular-like structures. In truth, what they are exactly is not known. What is known is they significantly increase pain and make it difficult for patients to trim their calluses.

These two symptoms of PC are not typically talked about in PC discussions but are clearly a part of life for a significant portion of the PC population. Data from the series of questions about these issues are being studied and will be published.

Thanks to all patients who participated in the questionnaire addendum to help researchers broaden their understanding of PC.

PARTNERING WITH A DOCTOR FOR THE BEST PC CARE

Because PC is ultra-rare, finding a dermatologist or primary care physician who knows a lot about PC is not nearly as important as finding a doctor who is willing to learn more about PC, work with, understand and listen to the patient, and connect with PC Project if needed. This is especially important when a patient needs a doctor’s care for infections or other PC-related concerns.

Some of the PC patients in our registry have cultivated positive relationships with their doctors. Click here or read the story below for an example of a dermatologist who partners with her PC patients:

MEDICAL COLLEGE OF GEORGIA PHYSICIAN HONORED FOR CARE OF FAMILY WITH RARE GENETIC CONDITION

The American Academy of Dermatology has honored board-certified dermatologist Loretta Davis, MD, FAAD, as a Patient Care Hero for her role treating a family with a rare genetic disorder. The condition, known as pachyonychia congenita, makes nails grow abnormally thick and causes painful callouses and blisters on the soles of the feet. This can make seemingly ordinary tasks, like standing, walking, holding items, or even breathing, uncomfortable and challenging for many patients living with pachyonychia congenita.

Buff Farrow of North Augusta, S.C., was diagnosed with pachyonychia congenita at age 16 by dermatologist Dr. Jack Lesher, who had...
also diagnosed her father, before Dr. Davis took over their care upon Dr. Lesher’s retirement. Farrow’s son was diagnosed at birth.

Dr. Davis helps the Farrow family effectively manage the condition and limit its effects on their daily lives. Because taking extra steps increases pain and causes blisters to form, the dermatologists helped the family acquire special accommodations, such as handicapped parking.

“Growing up with such a rare condition is challenging. The physical effects can be debilitating, but the psychological aspects of it are just as bad,” said Farrow. “While there is no cure for pachyonychia congenita, Drs. Davis and Lesher have helped us manage it as best we can.”

The genetic disorder is a result of mutated keratin genes that prevent skin cell filaments from properly forming. Less than 1,000 patients are on the International Pachyonychia Congenita Research Registry worldwide, but despite its rarity, the Farrow family credits the dermatologists for helping increase awareness of the condition.

“The doctor-patient relationship is always special, but it is especially rewarding to care for three generations of such an inspiring family,” said Dr. Davis. “Our dermatology division has learned just as much from Buff and her family as they have from us. They have helped improve our knowledge about managing pachyonychia congenita, which we’ve been able to share with our dermatology colleagues.”

The AAD created the Patient Care Heroes program to recognize physicians who transform patients’ lives by utilizing their expertise and collaborating with other physicians to treat serious skin disease.

“Living with a chronic condition—especially one that is rare like pachyonychia congenita—affects physical, mental and social well-being,” said board-certified dermatologist George J. Hruza, MD, MBA, FAAD, president of the AAD. “Every day, dermatologists like Dr. Davis help patients live life to the fullest while managing painful, serious, and often life-threatening conditions.”

To learn more about Dr. Davis’s work with Buff Farrow, visit https://www.aad.org/skinserious/stories-buff-farrow.

Congratulations, Dr. Davis, and thank you for caring about PC patients.

Birthday Fundraiser

Happy Birthday to Jessica White, who raised money for PC by creating a Facebook fundraiser in honor of the special day she was born. Thanks to Jessica and her supporters!

PC Superpower

Kerry Evans-Briggs, the winner of last fall’s meme-making contest requested her PC t-shirt prize to be for her son, Tony, who has PC.

Kerry wrote, “I honestly cannot put into words how much Tony loves his t-shirt. He wore it to school back to front, underneath his school shirt, just so when he unbuttoned his shirt he could rip it open like superman does. Then he flashed his friends the PC logo and declared that’s his superpower!”

“Because he’s running with the idea that PC is his super power, this is his pop art project.” Thank you, Tony, for sharing your PC power.
All the PCers in the International Pachyonychia Congenita Research Registry (IPCRR) are superheroes to us and to future generations! Thank you for participating!

You are helping to expand PC knowledge and are the reason why researchers and drug developers are interested in finding treatments. The summary graphs shown on this page are available online at pachyonychia.org/pc-data/

If you or your family members have PC and have not completed the online IPCRR questionnaire, consent form, and sent photos, please complete the forms online at https://registry.pachyonychia.org/s3/IPCRR or print a copy to fill out and mail at pachyonychia.org/patient-registry/

Each person who registers is vital to our progress. If you have questions, please contact PC Project at info@pachyonychia.org or at 801-987-8758.