During PC Awareness month in June, we witnessed the PC community come together as many donated, created fundraisers, and shared #WhatPCMeansToMe. Your words and photos inspired us—and taught the world what’s it’s like to live with PC. At the end of this newsletter, we included many of the posts so those who aren’t on social media can catch a glimpse of this neat campaign. And as you read this newsletter, you’ll see that if you have PC, you are not alone. You have a strong community of supporters who understand the challenges that come with PC, who encourage one another, and who advocate for PC in scientific and medical communities.

PC Project regularly gathers members of our International Pachyonychia Congenita Consortium of physicians, researchers, and pharma representatives to collaborate, present, and discuss PC-related research and drug development.

On May 18, 2022, PC Project hosted the annual IPCC Symposium in Portland, Oregon in conjunction with the Society for Investigative Dermatology Meeting. The IPCC Symposium was attended by over 90 scientists, clinicians, and
pharmaceutical representatives in person and virtually from all over the globe. Sixteen excellent presentations were given on PC-related research and drug development happening within our disease space throughout the world. Click to read the full program.

The evening before the meeting, we enjoyed a dinner with some of the attendees and invited local PC patients to join us. We know that some of the best scientific collaborations and discussions happen over meals and during breaks!

After holding virtual meetings for the past few years, we were thrilled to see old friends in person again and welcome new ones to our inclusive, special IPCC. And once again, we were grateful to see the incredible commitment IPCC members have to PC patients.
PC AWARENESS AT SID

After the IPCC Symposium, PC Project shared information about PC at the Society for Investigative Dermatology Annual Meeting at the Oregon Convention Center in Portland from May 18-21. We shared hundreds of PC brochures and postcards, collected contact information from professionals interested in joining the IPCC, attended key scientific presentations and poster sessions, and networked with numerous researchers and clinicians in our disease space.

We talked a LOT during that conference and love that PC and PC Project are getting more awareness in the scientific community. And as we network and teach about PC, we never forget the patients we represent!

We passed out stress reliever feet and told dermatologists they can squeeze these, but not real PC feet!

2022 SID Meeting and PC Project's Booth. Can you spy Janice & Holly?
Rare Skin Disease Congress in Paris

Some of the medical and scientific leaders for PC Project attended the First International Rare Skin Disease Congress in Paris on June 7-9, 2022. Professors Eli Sprecher and Edel O’Toole each gave presentations about Pachyonychia Congenita and PC Project, educating others about PC on an international stage. Thanks to our IPCC members who donate their time and efforts to our cause and who spread the word about PC!
Palvella Phase 3 Clinical Trial Update

First, thank you for the tremendous support we receive from all of you. Treatments cannot be approved without clinical trials and we are thrilled to be in a Phase 3 clinical trial for PC.

UK Patients: It’s finally your turn! Over 55 patients in the UK have signed up to be in the trial! Amazing! Those who indicated their interest have already started to be contacted. If you have not been contacted, you will be soon. Shout out to Dr. Edel O’Toole for personally calling the first set of study patients to set up appointments!

For those who said you were interested but live in a nearby country: We will contact you if we are able to include you in the UK trial. Because of restrictions, right now, only UK and US patients are able to be in the study. But THANK YOU for your willingness, and we will let you know immediately if circumstances change.

For both US and UK patients who still want to be in the VAPAUS study: It is not too late to sign up. Fill out the form registry.pachyonychia.org/s3/VAPAUS

Remember:
You must NOT have been in any PC trials in the past 3 years.

You must be over 18 years old in the US, or over 16 in the UK and have K6a, K6b, K6c, or K16 and If you do NOT know your PC type, we can send you a saliva kit in the mail for genetic testing right away once we review your registry forms and photos.

Most of the study involves putting a topical formulation on your feet each day on your own. You’ll also need to travel to 4 clinic visits over 8 months to one of the clinical trial sites following site locations:
• Portland, OR (Oregon Health & Science University)
• New Brighton, MN (Minnesota Clinical Research Center)
• Orange Park, FL (Park Avenue Dermatology)
• Austin, TX (DermResearch, Inc.)
• Palo Alto, CA (Stanford)
• New Haven, CT (Yale University)
• Salt Lake City, UT (University of Utah)
• London, England for those in the UK

The sponsoring company will pay ALL travel expenses for you and a companion for each of the 4 visits to one of these clinics.

More trial information is on our website: https://www.pachyonychia.org/vapaus/

If you have questions about the study, please contact us at info@pachyonychia.org or 801-987-8785.

In Loving Memory

One of our beloved PC community members, Nancy Berrian Bohnsack recently passed away too young from a short but fierce bout with cancer. She was diagnosed with cancer and only a few months later, she had left this life. Nancy was a huge supporter of PC Project and we had many wonderful interactions with her.

Admittedly, we are weepy just typing about our loss. That’s the thing about our PC family - we are tightknit, we care about one another deeply, and we hate that Nancy didn’t get to stay with us long enough to see if some of these exciting
treatments we are pursuing would have helped her PC.

We know a lot of you say you participate in clinical trials for the sake of the next generation of PCers and that is so appreciated. THANK YOU! But we also desperately want treatments for our patients NOW, including those who are aging. We want PCers of all ages to have the freedom of walking without PC pain at some point in their lives.

So we will think fondly of Nancy and continue to work as hard as we can to raise awareness and advance research and drug development for all of you! And please, never forget that like Nancy, you are all loved and cared for by us! You can read Nancy’s memorial here.

**PC AWARENESS: BIKING & ICE CREAM**

A BIG THANKS to the Wausau Wheelers, a recreational bike club, for supporting the Block family’s Ice Cream Social for PC Awareness Month. (The Blocks have a daughter with PC.) After their ride, the Wheelers enjoyed ice cream provided by the Blocks and individual riders generously gave free will donations that totaled $460 for PC Project! That amount was matched twice to make $1380 that will go to PC research and patient support! Biking is one of the sports many PCers can do and we so appreciate this group of cyclers for their kindness to PC patients!

**PC AWARENESS: IRONMAN**

PCers have the best supporters! Owain Robinson, a friend of PCer Tom Baker, is training for an Ironman and raising money to help PC patients while doing it!

After his first months of training, Owain wrote: "I’ve completed the first 10 weeks (base phase) of my 30 week plan for the Ironman Wales. It’s seen me ride almost 600km (excluding the dreaded spin classes!!), run 260km and swim 34km. There are a few missed training sessions but that’s the outcome of balancing family life and not wanting to miss out on time with them.

“Early mornings are the norm, as is eating constantly! I’m feeling good for where I am in the plan but know there is a long way to go yet. If you’re on Strava and would like to get bored of my frequent updates, please look me up – the support would be welcome @Owain Robinson

“Whilst this is a personal goal, I’d like the hard work and effort to benefit others and am raising money to support the PC Project. A close friend...
suffers with PC, an ultra-rare, ultra-painful genetic disorder with only around 2000 diagnosed cases worldwide. The condition causes calluses and blisters to form on the soles of his feet which can make walking extremely painful.

"And worse, being a genetic condition, his son has inherited the condition and also suffers. PC Project is the only organization in the world dedicated to helping PC patients and facilitating research for this disabling disease. They would welcome any support you can give and any and all donations mean a lot to this small charity. If it weren’t for this debilitation, I know that my friend, Tom, would be along with me on this journey."

Thanks, Owain! Tom and all your PC friends will be cheering you on from all over the world! Click to support Owain and PC on JustGiving UK.

#WHATPCMEANS_TO_ME

We had an incredible Awareness Month in June where PCers and their loved ones shared #WhatPCMeansToMe on social media. Enjoy some of the funny, heart warming, and real descriptions about living with PC.

Thank You!
LINDA - SHAWN - EVELINE
KIMBERLY - KATHY - JOAN
CHARITY - JOCEDYLOU

For creating Facebook Fundraisers
May-July to support
PC Project and help #CurePC

PC is pain. PC is misunderstanding. PC is embarrassing. PC is lonely. PC is anguish.

PC forces me to push harder and suffer more just to get through a day. I wake in pain, I live in pain, I go to sleep, hopefully sleep, in pain every day. When can’t run you walk, when you can’t walk you crawl, when you can’t crawl you find someone, something to carry you. -Richard, PCer

To see your daughter suffer every day and not be able to do anything. But she proves stronger than all of us at home. She has 3 siblings and she is our princess because we always have to carry her and she will always remain so. - Soumia, Mother of PCer
P for PC, p for pain - I am suffering with PC alongside with my father (some of my aunty and cousins) are also affected. I always tried to hide out my nails and foot from others. I feel pain whenever I make step. I know nobody will be able to understand the actual struggle of PC patients but themselves. Hopefully we will be properly cured one a day! Love for all who read and support.- MD Saifuddin, PCer

Pain with Compassion
I have been living with PC for 30+ years (but under a different diagnosis). I used to be carried around by my parents and older brother when I was a little girl. My toddler is recently showing symptoms of PC too. =< Having said that, I have been living with the pain (as other PCers in this community) throughout my life, but have also been able to learn from this unique experience (which is way beyond my control) to build resilience, perseverance, and COMPASSION for others and learn to not take things for granted.

As a patient myself and a parent of a PCer, I do agree with a post from a fellow mom of PCer that I want to help my toddler “see the blessings beyond the pain and to build empathy and perseverance in life”!

I am so thankful to be connected to this wonderful community (as I have been feeling so alone in the past years..). LOVE to share my experience with others and/or to be of support to others who may be impacted by this very rare condition. THANK YOU to this PC community! Love and hugs. - Kat, PCer

What PC means to me is pain, callous, and hopelessness. What PC Project means to me is hope, love, understanding, and support. Until I found PC Project and the wonderful people that truly care I thought I was all alone in this world. However I have realized that my life is complete and I enjoy the smaller things. —Jamie, PCer

PC is a very difficult disease to understand. Over time we have realized how difficult life will be for my brother who needed care at his young age. There are many activities that we want to do with him and we do not do them so as not to hurt him physically or emotionally. We have faith that one very close day they will find a cure! - Magdalena, sister of a PCer

Confesso que já murmurei muito por ter essa condição, mas Deus me mostrou que tem coisas que não posso mudar, e que Ele me sustenta em qualquer situação, então hj o PC significa pra mim FORÇA, é assim que me sinto, forte, porque não é fácil sentir dor todos os dias, muitas pessoas não entendem, acham que é frescura, mas só quem tem PC, é que sabe o quanto sofremos, mas também, o quanto somos fortes! Hoje tenho minha filhinha, que também herdou PC, e já se mostra muito forte, por sinal! -

To me PC means my daily “Personal Challenge” to manage the emotional and physical pain that effects everyday life including walking my amazing Golden Doodle... Stanley!
- Karen, PCer

This is Srikanth, my brother-in-law - PC patient.

Always in pain and isolation. He loves the woods and is an amazing but hidden nature photographer. Since he discovered the PC family, he has been more open about his pain and his interests.
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PC is pain, embarrassing moments, and every outfit I wear revolves around my feet.

I’m so glad for PC Project! For many, many years I had no idea what was wrong with my feet. Now I know.

- Diane, PCer

Growing up I was a vain girl, scared of what people might say if they knew I had PC. The embarrassment was worse than the pain at the time. Always thinking I’d never find love, or be able to hike, or swim with my friends etc. It runs in my family, so at least I’ve never been alone. It’s helped me at my worst to be able to relate with my dad.

It’s hard everyday but I’ve come along way. I’m in love and the way my feet are doesn’t matter at all to him. I just went to a water park and managed to get around in water shoes and wasn’t embarrassed. I stand all day working as a hairstylist and it’s hard but worth it. I think I can do anything, and it was life changing when I googled so many things and found the PC Project and found out it wasn’t just my family - there were others.—Jasmine, PCer

"PC is a very intractable (difficult or hard to deal with) skin disease and affects the quality of life of the patients." - Dr. Takashi Hashimoto, Osaka, Japan

"PC = Painful Curse — Swearing in response to pain may activate the amygdala which in turn triggers a fight-or-flight response. This then leads to a surge in adrenaline, a natural form of pain relief.

PC = Patient Courage

Growing up with PC I have always tried to hide. I hid the fact that I had PC. I wanted to hide my differences. I would hide my nails, my feet, my pain. It’s not exactly the first thing you want to show off or talk about. It has taken a lot of courage to be open about my condition.

Courage to talk about it publicly
Courage to educate others
Courage to show my true self
Courage to own this condition and not let it hold me back

Aside from myself, other PCers show courage by sharing their stories. We are all eager for a treatment or cure. We participate in clinical trials. I believe that without patient courage, the PC community would not have gotten as far as we are today. It only keeps growing thanks to the people of the community. Our courage to keep pushing forward and spreading awareness is going to lead us to a better future. A future of more acceptance, treatment options, and hopefully a cure one day.—Briannan, PCer

Constant pain and discomfort in my feet. - Sara, PCer

PC means thinking about every step I take before I take it to prepare for pain. - Diane, PCer

PC = Pain on my feet
Marissa, PCer

Pain and bleeding nails every day. Why should someone in this day and age suffer every day and night? - Stuart, PCer