PC Patient Support Meeting 2019

The 18th Annual Pachyonychia Congenita Patient Support Meeting (PSM) was held June 20-22, 2019 in Boston, MA. Sixty-three PC patients, along with their loved ones, clinicians, scientists and drug developers spent a day and a half learning from one another about how to best live life with PC.

A big thank you to our PC advocates and other volunteers who helped with registration, gave presentations, and led group discussions, including teen and children’s discussions.

Some program highlights included having patients group according to their affected gene. Patients who wished to could show visiting clinicians their feet and other PC symptoms. This educated physicians about PC in a profound and easy way.

Other program discussions and topics included PC research, clinical trials, PC pain, the social and emotional impacts of PC, being a loved one of a PCer, taking control of our health, how to help children and teenagers navigate life with PC, and being stronger than PC.

Special Report: Boston Patient Support Meeting

By Jennifer Hart

My doctor once told me I was his worst and best patient all rolled into one. What a compliment he was giving me! Let me elucidate. He said I was the worst because I wouldn’t sit down but the best because I’d never let PC beat me. How right he was!

Having struggled with pain from my PC over my entire lifetime, I had become resigned to just dealing with this as best I could. I had fallen off the radar of any specific medical care for the condition, but was satisfied that the podiatry treatment which I receive was the best support which I could expect. Then my daughter introduced me to the PC Project! My daughter Rebecca, who does not suffer from PC, works in Clinical Research so is very pro-active about all things new in human medicine. However, having been shown some of the information about the group by her, I still felt a fair amount of trepidation about joining as I did not want to get embroiled in a group just feeling sorry for themselves. This is, of course, as far from the case as is possible from the attitude of my fellow PC’ers who I met at the recent patient meeting in Boston. We are indeed warriors and determination is in our DNA!

I decided to book to attend the meeting, very much persuaded by my daughter that I would never know if I didn’t try. I’m not sure when my daughter started quoting me, I’ve used that phrase so many times in her childhood! Although having received nothing but warmth and welcome from both Jan and Holly in advance within various emails, I must admit to still feeling very nervous as I arrived at the venue. I shouldn’t have worried. The PC ambassador group at the desk was wonderful, and I immediately felt empowered by the possibility of what I was to hear and learn.

Over the next two days we enjoyed a variety of sessions, some informative and tutorial, some Q&A and others patient discussion groups. The mix was excellent. I found myself laughing out loud on the first evening when I realized that we were ALL limping. Now I felt “normal” and not the odd one out. This was in fact the first time in my life I had actually met a fellow PC’er.

So, my experience attending my first PC Project Patient Support Meeting has been positively life changing for me. I definitely have made new friends, but have also realised that I’m not alone in continuing to remain the best and the worst patient!

The last two pages of the NewsBrief contain a collage of photos from the Patient Support Meeting. Enjoy!
**Stronger Than PC Awareness Month**

Thanks to all who bravely shared PC stories, raised funds or made donations during PC Awareness Month. The Block family hosted their annual ice cream awareness and fundraising social. Briannan Buchta sold Color Street nail products to raise awareness and funds all month long in her clever “Pretty Nails for PC” campaign.

Steve Hall is doing a “Run, Jog, Walk 100 Miles” in August to raise funds for PC in honor of his daughter, Sara, who suffers from PC. Read more on his JustGiving Fundraising page at [https://www.justgiving.com/fundraising/Steve-Hall35](https://www.justgiving.com/fundraising/Steve-Hall35)

Many PCers also shared their stories on social media. Letting others know they have PC is not an easy thing to do. The interesting thing is not one person had a negative experience. In fact, many PCers were pleasantly surprised at the positive responses they received.

Michael McCullough shared his story on Facebook, along with some photos of his feet and reported, “My Facebook responses have been awesome. Some of my friends have never seen my feet before and have been blown away by the photos. Some of them have shared my story. One woman in particular shared the story with both her daughters who are in the medical field.”

In his shared story, Michael first gave an explanation about PC. Then he talked about life with PC. Here is a portion of what he shared:

I want to discuss a typical day in the life of someone with Pachyonychia Congenita. Each day can be very different. We have good days and bad days. Good days are those when some of us can walk and stand with mild discomfort. There is never a wonderful day. We are limited to the amount of time we can stand or walk. Running is out of the question. I played baseball when I was a kid. For me, hitting a double was torture. I could make it to first base with some speed but the resulting effort brought on a burning sensation in my feet. To have to run to second base wasn’t possible, the burning was too intense. To put it in real terms, if my life depended on it, I could probably run a block.

When I attended grade school, getting new shoes was an awful time. In the early 1960s, the dress shoes were terribly hard unlike the materials they use today. You literally had to break them in over a number of weeks. That was a bad experience. I cannot be thankful enough for the shoe manufacturers of today’s footwear. What a difference they make.

From day to day, we never know what kind of day it’s going to be. Sometimes, in bed, the weight of a simple top sheet or comforter over your feet is unbearable. I cannot tell you the number of times I’ve hung my feet out of the bed to sleep in peace. High humidity, rain, and snow are usually a bad day. In my case, the skin surrounding the calluses gets very taut. Each step stretches the taut skin making it feel as if it’s about to tear. In some cases, this actually happens. Sometimes a hot shower will soften the taut skin enough to get you some temporary relief.

I always walk with my head facing down to the surface I am walking on. Concrete, steel, and wood flooring are the safest for me. Natural grass or gravel is brutal to walk on because you cannot judge what’s underneath you. I look down because I need to make sure I am not treading on a stone. I need to see what’s in front of me; otherwise, I can trip or fall.
because one callus took the brunt of landing on a stone. For me it’s all about balance, in other words, spread the pain across the whole foot rather than isolating it on one or two calluses.

I mentioned earlier that my feet require maintenance. Even though I consider the callus dead skin it actually grows and thickens if not trimmed after so many days. I usually trim them every 7 to 10 days using single-edge razor blades. Some of the patients use Dremel tools or power grinders to maintain their feet.

Although my dad was well aware of our issues, he never told me not to play baseball or football. My mom also never let me feel like I couldn’t play like the other kids. So I did, and over time I built a tolerance for pain that I could handle. That changes as you age. It becomes much harder to do what you did in the past.

PC Project has been making a real difference in our lives. They have brought on many scientists and physicians from all over the world in an attempt to give us some relief and possibly a cure. If you have any interest in getting more information please check out the following addresses: info@pachyonychia.org or www.pachyonychia.org

Another story was sent to PC Project to be added to the website by the parent of a PCer named Olivia: You can read Olivia’s story in English and in Spanish on the website at https://www.pachyonychia.org/patient-stories/olivia-castro-lay/

Not only did Olivia’s family send photos of Olivia smiling and doing things she loves, but they also sent a collage of what affects her the most at her current age—the nail infections. Thank you to Olivia’s family for sharing.
Photos from the 2019 Boston PC Patient Support Meeting