

to me but I cannot do at all or as fully as I would like because of your condition. On the best days, I only feel a little burning on the feet, I can do anything with no worries. On the worst days, I do not want to do anything, because the pain does not let me sleep. Even the contact of the feet on the bed hurts, I cannot sit, stand or lie down without pain. I am 43 years old and I think it is more painful with the passage of time. My symptoms are better in the winter, with the cold weather. I live in Aguascalientes, Mexico, where the temperatures are usually hot, so most of the time it is painful. It gets worse if I remove the callus since the skin is very irritated. I have a history of diabetes in my family, I worry that this condition makes me lose my feet, I take care of myself by dieting and working out in a gym, but I still worry. This condition has affected my mood by causing depression, rather it's sadness, something of shame when I have to show my feet, pity when they smell bad. I am always looking for some shoes, socks AND tools for trimming the calluses, it is expensive some times.

Alicia K16 caregiver: Of all the symptoms experienced because of PC, PAIN, CALLOUS and ITCHING have the most significant impact on our lives. Family time that doesn't involve sitting down is an activity that is important to us but we cannot do fully as we would like because of PC. Sometimes, even sitting at a table hurts. We can't make plans because we don't know how those affected with PC will be feeling. We don't go to restaurants with certain types of tables, high tops or bars. The PC symptoms impact our lives because we can't do what others do without pain on the worst days we don't participate. Can't go for a walk, run around a playground with friends, play sports, swimming is even painful because the callous gets soft and you can't wear shoes. PC symptoms have gotten worse over time. Occasionally, it hurts so bad they crawl around the house. More callous and more pain. There is always pain but some days are better than others. Of course, if they overdo it the day before they pay the price the next day. However, some days are just bad for no reason. Sometimes they wake up in the night with extreme pain due to no reason. What worries us the most is the pain and how to live a fulfilling life with it. Future jobs and financial security and finding a doctor that won't laugh at us are also worries. PC affects our mood by getting frustrated, upset, jealous when we can't do something or when someone has to do it for us. My husband and daughter both have PC. There are nights he comes home from work barely making it in the house. When he does he crawls. Takes a shower sitting down. Then crawls to the bedroom and into bed. Where we have our family dinner and family time. He is a diesel technician. He works at a place where he can operate a 24/7 service truck. He loves it because he can sit while doing that. He has been headhunter and offered better jobs with better pay and benefits. He also suffers from knee, hip and back pain all associated with PC. However, he can't take them because they require too much standing. My daughter sits out during gym games because it hurts and she sometimes sits out while swimming because it hurts. She also occasionally crawls around the house.

Alison K6a caregiver: Of all the symptoms experienced because of PC, pain in feet and the inability to stand and walk for a long time have the most significant impact. Sports, dance, running and ballet are activities that are important to my daughter but she cannot do because of PC. On the best days- able to fully concentrate on studies and be active outside. On the worst days-hard to concentrate on studies and difficult to go out and lead a normal life. Over time PC is steadily gotten worsen, can walk shorter distances and stand for shorter periods of time. The

warmer the weather the worse the condition is. I worry that the PC is getting progressively worse. PC makes my daughter more determined and can tolerate a high pain threshold.

Amanda K16: I have a toddler that I sometimes have trouble caring for because I have trouble walking. I lean on counters and walls to get around the house when it's bad. I would love to run but it's hard. On the worst days I can barely walk. If I'm lucky one foot will be better than the other so I can limp. It was manageable as a teenager and got worse and worse through my 20s to my 40s. Thicker callouses and toenails. Harder for me to bend down and shave callouses as I get older. Hot weather and cold weather make them worse and better. That my young son will have to deal with it. No symptoms yet but he is only 3, my first callous showed up at that age. The pain makes me intolerant. I feel depressed about my feet and hopeless that they'll ever improve. I'm scared it will get worse as I age. My mother lived and died without a cure for this condition. Doctors never even knew what to call it. I have a little hope that there might be a real treatment in my lifetime and maybe a cure in my son's lifetime. Thank you so much to the doctors and researchers who are taking the time to care about this little known but debilitating condition! Much love to you.

Amanda K16: Pain. I'm a teacher and I often think about not continuing in this line of work because I can't reform the way I should for my students. Sores. I get many sores on my bottom and the top part of my thighs. They are very very painful. The more I sit, the more I get. And the more I stand, the more my feet hurt. It's a loose-loose situation. Everyday living. My mom comes over every weekend to do my dishes, take out my garbage, vacuum and clean. We both hate it. I can't shower. I have to bathe. It always takes a lot longer than it should. Hanging out with people or going out. It's too difficult. On the best days, I still have pain but it's manageable. On the worst days, everything is difficult and I have to crawl or avoid doing things like cooking. Everything has gotten worse and worse over time. I used to be able to do more when I was younger. I just found this spray called Deroplast. I've only used it twice but it actually helped the pain. I couldn't believe it. I use lidocaine for the cuts and sore spots but it doesn't do much. How am I going to be able to have kids and take care of them? I have depression and anxiety. I really need to go see a counselor. I seem to get frustrated easily.

This sucks :(

Amy K16: Pain has the greatest impact on my life because it prevents me from working, taking care of my daily responsibilities, some hygiene needs, and self-care of my condition. The pain also affects my relationships and my mood. Simple things like showering, cooking, and shopping are sometimes very difficult or even impossible. The majority of my pain stems from the blisters and callouses on my feet, cysts/boils in my groin area, my nails, and my mouth.

I had worked many years in a profession that I loved, but since being cut off pain medications and the worsening of my symptoms, I was fired from my job and have been unable to work since. This caused me to lose my health insurance and become homeless. I no longer have access to appropriate medical treatment and my family cannot afford to take care of me. I have become somewhat of a recluse because of the pain and embarrassment of my current situation. Even on my best days, I always seem tired. If I do go out, I have a constant worry that the pain will set in at any moment leaving me stranded in whatever environment I happen

to be in at the time. On my worst days, I struggle to get out of bed and think about giving up on life. My feet have become more painful and extremely sensitive over the years. While my nails were not previously an issue, many have become thickened and now grow curled into the skin around my toes. My nails have also become painful and sensitive. At night, my feet ache and sting throughout the night making it difficult to sleep. My hands sting and hurt when I wash dishes, drive, or other activities involving my hands. I now get cysts and boils that never completely heal making it difficult to sit, walk, and sleep. My mouth and lips get sore much more often making it difficult to eat and brush my teeth. My teeth have worsened with some that have parts chipped off. I also have arthritis which causes swelling, stiffness, and pain in my joints including my feet, knees, and hands and have been diagnosed with skin cancer. My symptoms are always there but change some in severity. Symptoms get worse with extreme heat or cold and too much activity. Rest and regular maintenance self-care such as scraping callouses, filing down nails, and keeping my feet dry help. Cysts seem to improve by draining them before they get too much pressure or infection and washing daily with Yardley's almond oatmeal bar or Hibiclens. I have been through two rounds of steroids over the last couple of months which helped tremendously with the inflammation and neuropathy in my hands and feet. That I will reach a point where I can no longer stand living with the pain and give up on life. One of the hardest parts of having PC is the lack of respect and understanding about the condition and the pain that it causes. I have spent my entire life trying to explain to doctors and even family members what I feel while being told "callouses don't hurt" or "you're just depressed" or called lazy because I can't take the pain of walking. I get very frustrated with doctors because they never seem to listen and think I am some sort of addict if I ask for pain medication. They insist on prescriptions that I have already tried and unable to take or did not work wasting time and money that I do not have. One dermatology specialist referred me off to a psychiatrist, which was incredibly offensive. But the worst, most depressing thing for me is having to tell my granddaughter than I can't play with her because of my "ouchies" when she can't understand how I seem okay one day and the next, I can barely move. It is incredibly frustrating and depressing to have no one to help you as you watch life pass you by while you sit in pain unable to enjoy all the little things that everyone else seems to take for granted.

I was prescribed and took daily pain medication (Morphine ER and Norco) for years which allowed me to go to school, work, and have a much better quality of life. I was abruptly cut off from these prescriptions because doctors are too scared to prescribe them and now refer patients to pain management clinics. After being unable to find a doctor willing to renew my prescriptions, I ended up getting fired from my job which caused me to lose my health insurance and become homeless. My doctors have been unable to get me an appointment with a pain management clinic because the majority will only accept patients with spinal injuries and require an MRI or x-ray to prove injuries. Because I can no longer get the pain medications that worked for me and am not able to tolerate or take NSAIDs, Gabapentin, Lyrica, or most antidepressants, I am left with no pain relief and unable to support myself. Without health insurance, I am on a nine-month waiting list just to be seen by a primary care doctor so I am stuck without access to any health care. I have taken so much Ibuprofen and Naproxen that I end up with bruises all over my body and draining cysts that I can hardly stop bleeding and so much Tylenol that I fear liver damage and neither really help control the amount of pain that I have. I am scared of using alternatives such as Kratom or illegal drugs for fear of damage to my

body and potentially overdosing on them. Lack of pain control also makes it difficult to keep up with my self-care treatments which causes my symptoms to worsen. Medications are of no use if patients do not have access to them.

Amy K16: Partially or completely limit my ability to participate in activities, limit my walking and limit my socializing are my top 3 symptoms because they impact my daily decisions on what I can do each day. I am in pain from the very first step I take every morning and have to re-prioritize every hour. I love to play tennis but I'm limited by the steps I can tolerate. If the temperature gets too hot it limits the steps even more. I have to fight being irritated with people around me because my feet hurt. It's depressing not being able to join in group activities because I can't walk/stand as long as others. I think my calluses have stayed the same.

I have been wearing Sketchers shoes exclusively since I had bunion surgery on both feet in December 2017. My calluses look considerably better but they are exactly the same amount of pain. My father was stoic about anything painful but as he grew older he was able to walk much less. His calluses became excruciating so it worries me that I will be the same.

I'm frustrated every single minute. I hate having to sit while socializing, care for my grandchildren while in pain and always having my family and friends make accommodations for me. Most of all I pray for an answer if my son passes it down to his children.

Andrew K16: Pain.. consumes my every thought. Financially it's expensive Foot Care wool socks only that are super expensive shoes that wear out very very fast painkillers visits doctors.

Simply playing with my kids walks with the wife hiking I used to love to hike when I was a kid exercise is nearly impossible for me. Peeing in the middle of the night and then falling right back asleep which I can't do cuz I'm in so much pain I would say on the best days there is some minimal impact. On the worst-case it's unbearable although I am lucky and I have really good painkillers that can help me grin and bear it through the situations Now that I'm into adulthood blistering has almost stopped because my feet are completely covered with calluses but I feel like the pain is way more noticeable and always on my mind I am always in pain no matter what getting off my feet helps taking my prescription painkillers helps overdoing it with my prescription painkillers and then overdoing it on my feet definitely can't cause great pain the next day but oddly some days there's no effect the next day just normal pain... I would say maybe 50% of the time after using large doses of painkillers I am in worst pain the next day

Worse and more painful by the years especially if it continues at the rate it has been from my twenties to turning 40 I can't imagine being 60 if the pain continues to increase at the same rate Everybody who knows me who knows I can be a real a***** to be around especially when I'm in pain and especially when they don't get good sleep because of pain especially when I have things I need to do but can't effectively because of the pain I'm a very difficult person to be around. It affects my wife the worst cuz I can be plain mean. I'm perfectly aware of it and somehow I still end up being mean and cranky But I was 30 years old I had great insurance and tried convincing my doctor in the surgeon to cut my feet off and build me prosthetics... They both refused.. 2010 I met with a pain management specialist who I begged to kill the nerves in my feet all of them with alcohol injections. He refused to entertain the idea because of the patients he treats with neuropathy from diabetes and the problems he seem

broken bones foot infections because you don't realize you've damaged your feet. He told me he would never do it to me and he didn't know a single person that would

Angela K6b: Painful feet Embarrassing nails Infections in nails Walking / exercising Taking part in every day activities Doing everything required in my job Always having to make excuses why I can't complete normal every day tasks Hiding my nails to avoid questions Pain has increased Nails have thickened considerably Much worse when the weather is hot That it will keep getting worse Depression Lack of patience It's very difficult to talk about my condition, I sometimes lie and say that I have a bad back to explain why I'm 'walking funny'

Anke K6b calluses, thickened nails would like to wear nice shoes (e.g. high heels or sandals) would like to do more outdoor activities such as hiking best days: no impact worst days: severe pain when I walk more calluses, more thickened nails (on feet) and more corn (? hope it's the good translation) dry feet make it worse, so I can not walk on (teva) flipflops the whole summer. Solution is to smear Nivea cream on my feet every night. Also a good pedicure helps that it only gets worse not so much, only when I have a really bad day

Anna K6a Pain Limitation to physical activities Limitation on shoes Dancing, hiking, tennis, all physical exercises Best day: do as much errands as I can and dance Worst days: just sit and rest my feet due to pain It has gotten worst as I aged. Developed new callus in different area of foot and more cracks It is just the level of pain that varies day to day and moments to moments. Use ice and pain medicine to feel better. Hot weather and socks with closed toe shoes makes it worse That it gets worst and how the foot will heal the blisters with diabetes Frustration and embarrassment when I have to cancel a physical event when my feet hurt Living with pain tires my body out easily and not able to do the physical activities is hard

Antonietta K6a Pain with feet calluses and blisters, nail infections, skin pain Travel, exercise, work functions Pain in feet limit activity Same Caring for my feet or the lack of doing it often enough may cause more pain It worsening Sometimes feel sad especially for my daughter who has to deal with her limitations with PC.

Aubrie K16 My feet hurt. I like to dance, jump rope, play soccer, and run around but my feet hurt so I can't do them much. On my best days I do all the fun things. On my worst days I watch television and my tablet instead of play. I have gotten more calluses and they are bigger and hurt more. Some days my feet do not hurt when I wake up. On other days my feet start hurting as soon as I stand and walk. When we go on trips my mommy and daddy make me sit in a stroller so my feet stop hurting for a little.

Ayla K6c My limited number of steps each day causes the most worry. I love the outdoors and being a happy/healthy/active person. I feel that my physical limits also limit my happiness and health. Hiking. Also, swimming or being in water has to be minimal to none because

moisture makes the pain much worse I manage my calluses with a razor blade. My family members are not able to do this because theirs are much worse. Mine seem to be a little better with age, but that could be because I am less active. Dry climate helps. I've noticed that when my feet start to hurt, I sit down to take a break. But when I get back up the pain is SIGNIFICANTLY worse. It's almost better to power through and never sit because it's much worse after taking weight off the feet. passing to my children depression It's much easier as an adult and people's thoughts don't affect me so much. But as a child, being picked on was really very tough. I remember children thinking I was gross or contagious. As an adult, I just wish I could enjoy activities more and vacations.

Brad K16 Pain with PC and appearance of PC Swim, walk on the beach, hike, play soccer, snowboard On the best days i can walk all day with minor pain, but still require lots of maintenance and care at the end of the day. On my worst days I can barely walk, even after soaking in a tub. And my feet require hours of care Callus has spread to over 95% of my feet. All toenails are effected and deformed. 2 fingers on my left hand are effected and deformed. Callus is forming on my hands. The pain is pretty much constant at this point. Warm bleach soaks help. Taping the deep cuts help. Keeping them dry and airing them out helps. Too dry is bad and causes deep cracks. Too moist is bad and causes blistering and necrosis.

Getting worse to the point of never being able to walk. Not being able to care for my feet as I age. My fingernails getting worse. Depression increases on the days when I cannot walk. I feel like I have to constantly worry about where I am and how long I can stand/walk before I can't anymore. I worry I will never find someone who will accept my condition and love me for who I am. Although I very much believe PC is my curse, I also believe it has made me a stronger person.

Brandon K6a Foot pain, nail infections Walking (especially hiking) Swimming in the ocean Walking is acceptable on the best days, impossible on the worst Use of hands difficult during infections Callouses growing larger, painful areas expanding Heat and humidity make symptoms worse Increasing pain as I age Frustration increases on bad days

Briannan K6a The painful calluses on my feet effect me the most. I'm always constantly needing my feet rubbed and I avoid doing any excessive walking because of the pain. I do what I need for work but hard to go out and socialize because of the added pain to my feet I would love to work out or go on hikes but limited due to my feet always in pain Best days I can ignore the pain and go on with everyday activities. At my worst days I get depressed and with I could just cut my feet off because of how bad my feet hurt or bother me. I feel over time as I get older I'm more sensitive and my pain is getting worse. Come and go, yes. Massage helps pain. My feet getting hot and sweaty make it worse I think. Not being able to walk in the future I get depressed and feel bad that I can't take part in some adventurous activities Still looking for a pain reliever or shoe that will help

Buff K6a The foot pain, without a doubt, has the most significant impact on my life. I think about just about every step I take and plan to minimize walking. This has a huge impact on my emotional well-being ... the chronic pain and the stressors that come from it. The worry I

have for my teen son affected with PC multiplies the negative emotions and stressors I have because of PC. Absolutely. I worry a lot about my general health as I age, since my options for exercise are limited. Things as simple as going to the mall with my teens are truncated by how much walking I can tolerate on any given day. On the best days, I have minimal walking outside of my normal home/work routine. I still have to think of every step, but it's bearable. On my worst days, I feel depressed on top of the pain. I feel defeated when I have to decline invitations or modify a family outing bc of my pain caused by PC. I would say over all my condition has stayed the same or gotten slightly better. That could simply be down to the fact that I am better able to manage my PC. As a child I had many infected nails and lots of folliculitis. Those are both exponentially better. My worst period as an adult was when I taught school. My decision to stop teaching was heavily influenced by my PC pain. My symptoms do come and go. Weather, level of activity, shoe choice and my prophylactic care of my symptoms all influence to some degree the symptoms on any given day. I have learned to cope with my PC. I have a career that I love and is manageable I'm regards to my PC symptoms. I do worry that I will no longer be able to wear flip flops at some point due to blistering or callousing between the toes. This would be a HUGE life changer for me. My greatest worry is that my son will have greater difficulties in college and finding a career that he loves and is manageable in regards to his PC. My PC has only had negative effects on my mood, although I try very hard to not let it get the best of me. I feel sad when my activities are limited. I feel dread when I have an extra activity - like a kid's ballgame - that I know is going to involve extra walking for me. I hate shopping ... not only bc it's painful ... but bc I can't wear cute shoes. I feel sad when I can't get manicures and pedicures with my daughter. I am undoubtedly more irritable and impatient when my feet hurt. I'm sure it has had a negative impact on my relationships at times. I worry a great deal about my son with PC. My 16 year old son also has type I diabetes. I asked him one time if he could choose a cure for diabetes or PC, which would he choose. Without hesitation, he said PC. This speaks VOLUMES.

Carl K16 Inability to participate in sports, reluctance to have children, limits travel Walks with wife. Hiking, hunting and stream fishing. On best days there are few limitations Worst days - the pain can distract from work or conversations They have worsened over time. Yes, but I have never identified a reson. Lack of mobility and an inability to self care for feet when older Patience and tolerance can be an issue when feet are at their worst.

It can be a difficult discussion when considering a potential mate. I admittedly did not know enough about the condition when I was at that stage of my life and had learned little more until encountering the PC Project just a few years go.

Carmen K6a Difficult to walk and keep standing, like in a queue to pay, walking in a shopping mall. I just can't do it. Participate in familiar vacations because I cannot enjoy them Need to rest during the day, constantly confuse with laziness Sports, participate in familiar vacations, shopping, walking with my dog On the best days not a problem. I try to forget pain with meditation. On the worst days, I cannot stand up or either use any kind of shoes. Just rest . Perhaps now I am more used to live with pain. When people ask me why I am walking different I realize I am in pain. I try to enjoy life Try not to think in the pain but in the time I am enjoying Nothing. I can still use a wheelchair to move in the future Have not bought on

yet because I think one better may be built. Always think positive. A bit of depression Tolerance to frustration for not doing what I want but what I can Thank to my family for their support since I began to have pain (or since I remember). Comprehension of my brothers and sister, 7 in total, who incorporated me to their games even when it to me longer.

Carol K6a Comments by other children and some young adults No. On good days not at all. On the worst days I can't take long walks. I have more callouses. Using foot powder and sometimes soaking my feet. Always wearing comfortable shoes. Spikes are not for me. This has been so even when I was in my twenties. Nothing now because I am 78. When I was young, I was glad it was the style to wear gloves. Not at this time.

Catana K16 1. walking 2. foot callouses 3. pain Walking All are worst days. Symptoms have gotten worse. Walking makes them worse. It is getting worse. Yes, all of the above. No.

Timothy K6a "Painful calluses/blisters on the soles of your feet Painful blood vessels/nerves in calluses Infections in nails or feet" Walking without discomfort On the best days it limits the time I can spend in physical activities. On the worst days it eliminates and physical activities. As I age, my endurance is less. Symptoms have not changed. Worse in hot or warm weather. Summertime is difficult for calluses and blisters. It is permanent. wont get better and most likely will worsen with age. My condition is inherited and I remember how my mother suffered in her aging years. On bad days it causes frustration with the limitations. I am a father. I have two children with PC and two Grandchildren. I am concerned with the challenges they have and will go through in life, living with this condition.

charles K6a Feet- unable to walk more than a few miles or multiple days. Finger nails - cracking around nails. Hiking/backpacking. Multi day cycling events. Best - none Worst - unable to walk Gotten better. Likely due to management Better - cool temperatures and limited walking Worse - heat. wet shoes. Once they are blistered I'm immobile. Ability to trim calluses as I lose flexibility. I am super tolerant.

Christine K6a Callouses and foot pain - limits walking and standing. Sports such as soccer because of the running and foot pain. It is gradually getting worse with age, weight and activity. There is always some foot pain but it is less if she is not standing or walking as much. Cool and dry weather also helps. Not being able to participate in school activities. The pain and walking limitations will affect career options and college choices in the future. Frustration because she would like to do everything her friends are doing.

Claudia K6a Infections in/around nails: because they cause pain (and even hospitalization+surgery) interrupting sleep and normal manipulation of objects during development (for example using buttons or colouring can be painful) Pain/ blistering on feet: because it limits walking or sleeping Follicular hyperkeratosis: some of the lesions have grown and cause itching and pain for example when they catch on clothing or if touched example

dressing/undressing are difficult He would like to be able to do normal child activities like running, colouring, dressing, learning to write without pain. On best days some pain from follicular hyperkeratosis or fingers. Worst days great pain/hospital admission It has worsened to include more symptoms or greater severity of previous symptoms Heat makes them worse. Petroleum jelly helps protect feet. Chronic pain management Irritability or anxiety on bad days Has anyone reported a special intolerance of or sensitivity to heat? For example, my child cannot stand warm water for washing his hands or bathing that the rest of the family recognize as suitable. He will scream (as if it were scalding him) and insist that even just barely warm water is too hot. I wanted to know if this could be related to PC... Thank you.

Danielle K16 The pain is significant, some days I'm fine and others I don't want to walk, possibly due to some harsh activity or swimming done previously. The thickened nails, some toes look like they are starting to thicken, they go from normal growth to thickened calloused mess, and no telling if they will return to normal or just stay thickened. Callouses sensitivity & cracking, if they grow to large the callouses will crack. I may end up picking at them and risk infection, so I must sand, shave, or clip away till they are even surface. If it's uneven, walking is a pain because I can sense even the slightest unevenness. I love running and parkour, but I cannot perform or attempt anything of those natures without pain. I have to consider giving up my dream job ideas because I may not be able to handle the physical demand. Participate in games or sports is hard because the activity hurts my feet. On my best days I can ignore the pain usually. I may forget I even have issues, and just walk the house barefoot or with slippers. On the worst days, I don't even want to walk. I'll try to stay seated or laying down all day just to rest. Standing on my feet feels so painful, I'll be limping and grabbing things as I pass to balance myself and help walk. Yes, the callouses are spreading over larger areas and more nails seem to be thickening. Some callouses look like they disappear, but new ones grow in other areas. Sometimes a blister or sandpiper on my foot becomes a callous. The pain seems to come and go, but I may just be used to it, I feel I cannot say for sure. I remember one year I had trouble sleeping because it felt like my feet were on fire at night. Water causes them to hurt, so after swimming or a bath I'm very "tender footed" and look like I'm walking on egg shells. Shaving the callouses off with a razor leaves me with raw skin, which will eventually thicken and just regrow as callouses, but when freshly shaved the next few days are very painful. That it may one day take over the whole bottom surface of my foot. What job will work for me with this condition? How will I work? What about bad pain days at work? I worry about my future a lot and was depressed and upset about my condition. I (as a child) was also upset people never understood what I was going through, and often felt like I was "weird" and useless. I use to feel depressed about my foot condition because it made PE so difficult. Elementary was a nightmare because my coaches thought I was just lazy or overly sensitive when I told them how much it hurt to do laps or run. My mother swore I could just shave them off, and she would try shaving and sanding them off, all which hurt. People thought I was lazy or wasn't doing a good enough job to care for myself, when the truth was I was trying everything. I felt humiliated and depressed about my feet.

Darlene K6b pain with walking and standing having to file toenails and shave calluses every 2 weeks shopping for shoes with a thick memory foam insole walk longer distances

with family members best days I can walk downtown to do errands and worst days If I have been on my feet most of day then I have pain, burning and throbbing beneath the calluses at the end of the day. second and third toenails were the last to thicken over time also a callus on outer part of left foot below little toe has extended downward and thickened causing this area of my foot to widen I always have pain standing and walking pain increases as I continue to walk the hot summer heat increases the pain I cannot walk on gravel or a sloped sidewalk I notice I am able to walk barefoot on a sandy beach with less pain also sketchers go walk 3 have helped lessen my pain due to the thick memory foam insole and the pods on the sole of the shoe which help decrease pressure I have lived with my condition for 48 years . I was 20 years old when my blisters and calluses started forming when I was constantly on my feet in nursing school I was diagnosed at age 55. I am now retired but I worry about my three sons in their late thirties with PC and two grandchildren with PC having to endure the foot pain in their young lives frustration with the pain and unsightly calluses although having PC has made me mentally stronger to soldier on while in pain during my raising a family and nursing career. There have been times when I would be close to tears with pain after my shift and would be limping when I arrived home My 93 year old mother has PC and I file her toenails and calluses. Since she doesn't walk as much due to a stroke and an arthritic knee the calluses on her feet have decreased in size!

David K6a Knowing that I need to work to provide for my family but I'm limited because of the pain. It's not embarrassing it's just life. The pain just becomes overwhelming. Playing with my neices and nephews as well as outdoor activities. The hotter it is outside the worse it is. I love to fish and hunt but limit the walking I will do. The best days are when it's freezing cold out and my feet I guess go numb and I feel like a normal person that doesn't feel any pain all day. On the worst days, I want to crawl around on my hands and knees to avoid walking at all cost. The conditions haven't changed. I've become aware of what helps and what I need to do daily to make it more comforting. Cold weather is better as long as I lotion my feet. Trimming down the callus with a razor blade but not low enough to cause bleeding. There has to be some callus there in certain parts of the feet, other parts not. Warm weather is the absolute worst. Everything about the heat hurts. Ibuprophen is the only thing that really helps. I found that Aleve and naproxen make my feet blister really bad. Passing it on to my offspring and watching them grow up in pain like my family has had to. My father and oldest sister also have PC. Not as much now as it did grown up and hearing all the name calling. I've excepted it and it's just the hand I was dealt in life. Noon at the moment.

Denise K16 1. Pain. My feet hurt everyday. May change in intensity, but there is always pain. I have to think about what I my daily activities are going to be and how to manage the pain that I know will come. 2. Embarrassment. I am embarrassed at how my feet look. This goes into the clothing that I wear because I am limited on the shoes that I am comfortable in because of the pain in my feet. No cute sandals for me. 3. I work as a nurse in the operating room. I am able to manage the pain, but due to taking NSaids, my kidney function has been negatively impacted. I rely on the pain meds to get me through my shift. My husband and I rely on my job for our income. I can't hike, go for walks on the beach(without tennis shoes), limit my activities with my grandchildren, everything that includes being on my feet. On my best days I am

not active. The pain in my feet is tolerable without medication. On the worst days my pain can get to 8-9 of 10 and I just can't walk or do any activity that requires me to be on my feet.

I don't remember having as much pain when I was younger. I played high school basketball and track. I don't really remember when the callous got worse. Now I rely on custom insoles in my shoes to provide support and softness to allow me to work as a nurse. No, my symptoms are very predictable. If I don't keep my callouses trimmed the pain is much worse. If I walk too much today the pain is worse tomorrow. Walking on hard surfaces is impossible. Even walking on the beach, (I live in Florida) is too hard. Or if it feels ok, my feet will hurt later. My pain is better by using custom insoles in my shoes. The insoles do limit the shoes I am able to find that they fit in. That I won't be able to keep the pain under control to continue to live how I want to. I feel awful that I have given this condition to my children and grandchildren. At times I feel sorry for myself that my feet hurt and I can't do what I want to do. But I am able to keep it in perspective. Things could be a lot worse. Mostly I am embarrassed to tell others that I have PC and have a disability parking pass. It was wonderful to finally find out that my callouses were caused by genes not something I did. The condition had a name! I thought our family was alone with this. Many thanks to the PC project in their help with information and providing the ability to provide support with others with PC.

Denise K16 Living in pain. Caring for myself as I grow older. Lack of ability to participate in activities. Would love to be able to go to the beach with my grandkids. Can't walk on sand. Can't walk on grass. Any activity I can participate in gets cut short because of the pain on best days. Can't participate at all on worst days. Yes. Pain and disability have gotten worse over time. I rely greatly on cane, rollator, and scooter. They never go away. Pain is more acute while standing or walking. It becomes throbbing while sitting. I sit and elevate feet to try to get some relief. Pain gets worse if I stand. That I won't be able to take care of myself.

Depression. It makes me feel isolated among a group of non-PCers because I can't really join in and be like anyone else. There's always a restriction or modification or an accommodation that I need to participate.

DHARA K6a Dor ao caminhar e aparência das unhas e pés. Por que me limita em certas atividades e questões de auto-estima. Sim, como por exemplo praticar alguma atividade física e um hobby que é dançar, pois a dor no pé não permite. Nos melhores dias é algo tranquilo, jáj me acostumei com as adversidades, porém nos piores dias é bem complicado me virar, ainda mais quando se mora sozinho, as tarefas diárias da uma casa nem sempre podem ser feitas. As bolhas nos pés vem diminuindo bastante, em relação a frequência, agora as unhas inflamam apenas quando machuco, a pele áspera vem ficando mais macia e o calor não faz tanto efeito sobre meu corpo. Alguns sintomas vêm e vão, como por exemplo as bolhas nos pés. O que melhora isso eu nunca observei, pois todos os medicamentos que jáj usei, nenhum faz mais efeito. Jáj o que piora é a poeira, o calor e meu emocional abalado de alguma forma. A dor em relação a um futuro emprego, por poder ser um empecilho. Quando mais jovem, na faixa etária dos 9 aos 14 anos, tinha crises de existência, me perguntava muitas vezes o porquê disso, frustra mesmo, evitava conhecer pessoas novas com medo de rejeição, sofri bullying na escola, mas depois disso, comecei a estudar sobre PC e tinha mais argumentos para falar sobre o assunto

tranquilamente. Hoje em dia, por todas as minhas conquistas, me sinto muito bem, uma guerreira. Estou feliz pelos rumos que o projeto está tomando e viver com PC pode ser uma forma de auto-evolução, pois temos atitudes, que muitas vezes, são difíceis de conseguir. E pretendo mostrar/falar mais sobre PC a cada pessoa que conhecer.

Diane K6c Pain Hiking long distances On good days when I don't have much foot pain, I feel thankful. On my worst days with foot pain, I feel irritable and angry. Now that I am retired, I am not on my feet as much so my condition has improved. However, my 16 year old son who has the same condition as I do is suffering with foot pain most of the time, especially through baseball season. Not sure if he will be able to continue. My symptoms improve when the weather is cold and dry. Also, when I am at the beach and walk barefoot on the sand, I can do that without pain. This is not the case when I walk barefoot on other surfaces. My symptoms get worse the longer I am on my feet and is accelerated during the summer months when the air is moist and hot, I worry most about my son who has this condition. He is 16 years old and is currently involved in baseball and other sports activities. I see the impact that this painful foot condition is having on him, I worry about how it will affect him once he enters the workplace. I worry about the possibility of my future grandchildren having this condition, When my feet hurt, I have a tendency of becoming irritable.

Diane K16 Pain, pain. Pain I can't do all the activities my family does because my feet hurt and are painful. I wish I had other job opportunities that didn't depend on the pain in my feet. My PC has issues everyday with my life activities! Everything I do depends upon how bad my feet are hurting, my shoes, my clothes, everything. I think the pain has gotten worse over time. I've had to take more prescription meds for the pain. The itching on my feet comes and go, I'm not sure what makes it better or worse. Is it going to get worse so I can't handle it? How am I going to take care of my feet when I get older? I get frustrated, and discouraged, and I really wish I didn't hurt all the time. But most of the time I can handle it, I only wish I could do more activities and I didn't hurt so much. I really dread thinking about going through TSA security at the airport. Do you know how much my feet hurt making me take off my shoes? Horrible! I love swimming but when I swim like houses get soft then my feet really hurt! I can't even walk on them then.

Diane not known Ugly, thick nails. It's socially embarrassing. Thickened skin on soles of my feet make it very difficult for me to go barefoot in the summer and at the beach like everyone else. Walking barefoot. Especially at the beach. Every day I am conscious of ugly nails and try to hide them and am embarrassed when meeting new people. I take care of my feet but on those occasions that I get an infection, it makes walking very painful. I went to Hershey Medical Center for several years. The doctors there put me on Fluconazole 250 mg. once a week. It has really helped with keeping the infections to a minimum. Also, they suggested and I now use a barrel sander on the end of an electric Dremmel tool to shave down the thickening on the bottom of my feet. These 2 things have helped me dramatically. My symptoms are constant. That I won't be able to care for my feet as I get older. I'm not as carefree as I would like to be because I worry about constantly having to explain why my nails are so ugly.

I really wish there was some way to prevent passing this gene on to future generations. It pains me that 2 of my 3 children have to live with this condition, also.

Diane K6b Pain- I have to limit my activity; I have to plan for activities and save my feet for them. Time- that it takes to maintain my feet. Appearance- I am embarrassed for people to look at my feet, I stress on wearing open shoes/sandals in summer. I would love to take long hikes, but I fear that the terrain would be too rough on my feet. Beach walks are best. Best days- I just don't care what people think. Worse days- I get angry that I have this issue. When I was younger my dad did my feet, now I do them, almost daily, I have a routine which I think has lessened the depth of my calluses. My dad has it much worse than me, and I have it worse than my daughter...it seems to be fading out. I always have them, but since I have been taking both natural Apple Cider Vinegar and Turmeric I have noticed that the pain is much less and that the calluses seem to be thinner. That there will be no one to help me with my feet when I get older. That my grandchildren will have it. Only one of my 3 daughters has it and it is very slight. I just deal with it, my mom always said "God only gives you what you can handle." I was born with webbed hands, I am not sure if this was an offshoot of having PC. No one else in my family on my mother's or father's side has had this.

DjoekeK17 Pain, limit activities, limit work/job Walking, Every step hurts Dance, I can't do that I have to much pain Best days mild Worst days severe Gotten worse Always there Frightened that someday I can't walk anymore Depression/frustration. Not willing to accept that I can't do anything I want to Never let you get operated on your feet for PC!!! Scars give you even more pain!!!

Elie K16 Limit my standing Limit my walking Limit the types of jobs I can realistically perform running, sport best day : less pain, can't stand or walk bad day : pain all the day and night, make me mad at everyone in the world getting worse until 2014 and stable now, I am in wheelchair and never walk, NEVER... getting worse if I stand and keep my shoes a long time. betting better if I do nothing and with no socks and shoes. PAIN PAIN PAIN never be able to stand and walk Depression for sure for a long time now, but I have kids Frustration every single day I have tolerance and patience but while in pain, I am completely mad and don't want to see anyone It is very hard to see tears in the eyes of my wife sometimes because it is very hard for her. I want to walk with her and do some shopping without my wheelchair like a normal husband and see her eyes brightening of happiness

Elina K16 Pain, embarrassment, running out of comfortable shoes lol. I'm a nurse who works 12 hr shifts. If I have the wrong shoes, I can't describe the pain my feet feel after. No one at work knows and I don't take meds for it. Yes, hiking, being freely active with my husband and 3 little kids. If I've worked the previous day, it takes me a day to recuperate, which impacts what I can or cannot do with them. Best days: constant pain but I deal with it. Worst days: worse pain which I just get through. Sitting helps. Soft slippers help The calloused seem more painful today than say 10 yrs ago. No, the pain is always there That My life will be limited. But, I don't think I'll let it. Life is beautiful. God is good. Just frustration.

Elise K16 pain on feet > can't hardly walk. limits me in all kind of things pain on hands > limits me in writing and all kind of other things which I should do with my hands Thick nails > limits me in fine motor skills, suchs as close bottons, open packs etcetera socializing with friends cannot spontaneously. If they go on a bike to the city and then walk around. I cannot go with them. I can ride on a bike to the city but than I don't have a walking bike to walk through the city for example. Doing sports is also difficult. I cannot play soccer or tennis. On the best days, I have pain but I stay positive. I try to work at my condition. On the worst days I have extremely much pain and I have to try not to get a qaurrel with everyone I learned to accept my limitations more, but that is still hard to do. I worked a lot at my body with Pilatus. That made me stronger so I can handle my pain better. The Symptons are Always there but at bad winters are the symptons the worst. I do Pilatus to get a strong body and walk (the little distances) better and I also get mentally stronger. Hearby I can handle the pain better If I can get a normal job and a wife and children I was really frustrated for a long time. Children at school are bullying me and I was very sad. Why do I have this disease. Now its getting better, but I am always strugling and fighting inside of me. It's very hard living with PC. people don't understand it mostly, so you have to deal with it yourself or with your family. It's very lonely

Eliza K6a Larynx growths are a very serious and potentially deadly syptom of pc. There has been 3 infant dearhs in my family because of these growths obstructing the airway. My daughter had serious medical issues as a infant due to growths i her larynx, and had 5 laser surgeries to improve her ability to breath. Daily pain is a huge syptom that affects every aspect of a patients life, and dealing with daily pain can lead to a hpst pf other medical problems. For example, joint and back problems, stress induced illness, depressions, etc. My childrens activities, when others are planning an event or activity, I have no control over my own plannong as I cannot always predict how to prepare for tgw cirrcumstances. This is especially hard with my kids events. I eant to be there to watch them and celebrate with them, but having to walk or stand on gravel, having no access to seating, beong asked to remove footwear, etc can hinder my ability to participate in even watching them in activities. Every day there is worried planning for the worst, because every day has the potential of becoming a bad day. Pain is a powerful distraction, mood altering, loss of appetite, sore back, ankles and knees, trouble sleeping, stress, depression, swelling. On bad days everything, and i do mean everthing from brushing my teeth, going to the bathroom, getting to work, even sitting to do anything, is an enornas effort. On good days, the effort is lessened on accomplishing the tasks, but the worried planning and caution to maintain the good day is all consuming then.

Worsened, it is very hard to care for and rwmove calus with all the nerve I have on my feet. The harder it is to rwmove calus, the more it buolds up and the worse my pain gets. It is a cycle that grts worse with every year. I often wonder if amputation would be a better option.

stress and hormones make it worse. A good clean diet helps in how bad my swelling gets. Longevity and the lack of ability to enjoy my life. depression is a side effect of pain, they are linked. It is hard to function in relationships with my spouse, kids, and co-workers when i am in pain. Pain makes me mean and short tempered. All I want is hope for things to get better rather than the knowlendge that my condition will get progressively worse with age.

Elizabeth K16 Pain while walking, feeling like I have to hide my finger nails because they're so thick. These are the two that have the most impact on my life because I don't like to explain why my finger nails are how they are and sometimes my job requires me to walk or stand for longish periods of time and that can be very difficult and painful. I love to go to concerts with my girlfriend but sometimes it's really hard because that's a LOT of walking and standing. I also love playing hockey but skates are hard on my feet, so I don't play anymore.

Best days: my foot pain is always present but on my best days it doesn't affect me very much. Worst days: my foot pain is so bad that it's hard for me to even walk to the bathroom, these are the days that I try to just lay in bed all day because that's the best place to rest my feet. It has slowly gotten worse, it takes a while to worsen but I have noticed new calluses forming. My symptoms don't really come and go, they're always present but sometimes they're worse than others. I'm not really sure or something names my symptoms worse or better. That it will progress so much that I won't be able to walk at all. Usually I can just accept that I have the foot pain and try really hard to not let it bother me, but sometimes it makes me really frustrated, angry, and depressed. The PC Project has changed my life. My father has always just accepted that this is how his body is, so he never tried to get answers for me, but my uncle found the PC Project, was tested and was able to give me answers that I never thought I would get. I have learned a lot about my PC and my genetic mutation because of it.

Emma K16 PAIN!!!!!! The pain of just walking keeps me from participating in daily activities with my family. Going for walks/hikes. Taking care of my grandson. Traveling. On my best days I can push through the pain to join in activities. On my worst days I simply have to miss out. The calluses have increased...meaning more pain and more time caring for them.

Staying off my feet helps reduce the pain. The more I increase my activity, the worse my pain gets. That we won't find a solution to relieve the pain in time to help my grandchildren. I lack patience when I am in pain.

Erin K6b Painful calluses on my feet I would love to be able to hike, run, or play sports, but my ability to do so is very limited. Best days: I experience some pain with walking. If I limit my walking and standing, I may be able to avoid painkillers or cutting out activities due to my PC. Worst days: pain even when sitting. Walking or standing are agony. I have to take large amounts of ibuprofen even to function I get fewer blisters, but more calluses. My feet are more painful, and I have more thicken nails on my feet. My hands now have a few small callused areas, which they didn't before. These can also be painful, depending on what activities I am trying to do. The symptoms come and go. Painkillers help, as does limiting the amount of walking. Keeping calluses trimmed down also lessens the pain somewhat. I find cold better than heat. I wear cushioned sandals or slippers, and avoid shoes. It limits the type of employment that I can do, and that has caused worry in the past. On bad pain days, it is difficult to do anything, and it gets very frustrating. Having to limit my activities is also frustrating. I do suffer from depression as well, but I am not sure how much of that is related to PC.

Erin K6a Pain, mobility limitations, infections I would love to travel more than I am able. I was unable to play any sports as a child and it limits the types and duration of exercise that I can do as an adult. Some professions are unfeasible for me that I might have otherwise pursued and I have to modify my work at times due to pain and mobility limitations. Best days: discomfort and some embarrassment. Worst days: severe pain even when lying down, cannot walk or stand more than incidentally, cannot climb stairs (my bedroom and bathroom are on the 2nd floor - have to crawl), have to put off work or chores. Yes, they have worsened on the whole. I experience more pain, worse calluses, and my mobility is more quickly affected by activity, however, my number of infections and nail loss has dramatically improved with age.

No, they are always there. Better: rest, heat, dry; worse: cold, wet, activity - especially standing That it will become worse and worse as I age (may need to use a wheelchair or other assistive devices full time); that my daughter will have a worse case than I do and be limited On bad days, my temper is short. I suffer from clinical depression and anxiety and although I don't think PC has contributed to them, it definitely make my bad mental health days worse. I feel very lucky and blessed to have as mild a case as I do. I know many patients suffer far worse than I do. I live with daily pain, but overall, I am still able to live a full life and do most of the things I want to do. That may change as I age, but I still feel lucky overall. I am desperate for a cure and effective treatment now that I have a daughter with PC. Though I pray she will have as mild a case as I do, I still want her to live life to the fullest with minimal pain and suffering, just as any parent would. Maybe her children (if she chooses to have biological children) will have a way to be completely free from the burdens of PC.

Esther K17 sebaceous cysts thick nails blisters on sides of feet and toes I have been alone for over 30 years because the cysts are ugly and get infected. Depression Cysts are not as numerous, but still there. Only age seems to have made them lessen. I'm always worried someone will see my skin and feet. depression It won't kill me, but it has made for a lonely life.

EVA K16 Pain walk long distances practise any sport I can't walk or stand for a long time on best days. I can't even stand on worst days My calluses affect a greater part of my feet They're worse with heat or humidity That are getting worse as I get older and not to be able to be autonomus my patience is less as I get older

Fabiane K6a Thickened nails and calluses Running or walking long distances I am a woman, and I can use nail polish. However my 4 year old son cannot. His PC is worse than mine and it makes me sad to have to explain to his friends or people looking as if i didn't care for his nails just because they don't know PC, people really think it is lack of hygiene and that makes me angry Seems that nails are getting grosser and more follicular hyperkeratosis are showing up no. always there impact on my child's mental health, bullying and etc My condition is not bad and I hide with nail polish very well, my calluses are not big as well, so it is fine for me does not affect my mood. I think it is important to use social media to teach people about PC conditions and other nails issues. I have seen people saying " even if I had a genetic problem it makes no excuses to leave your nails like that". People just don't

acknowledge the fact that even when we cared for the nail the most we could, it still looks ugly and disgusting in their eyes.

Fran K16 1- pain 2- infections 3- body pain from walking wrong sitting down does not work for me. I choose to be active and take over the counter meds to help me through whatever I can handle. I would like more...e.g hiking...running...walking long distances every day the worst days seem to occur right when there is a lot happening in life. Puss...pain..water blisters that remove chunks of callous to reveal raw red meat suddenly appear right at the time i thought everything was going well my hands and feet are completely covered. I cannot sand my feet or cut my feet. I gave that up many years ago when the red nerve endings revealed themselves. The callous grew back and has become hard so it cracks even more. Humira helped for awhile but I can no longer take it due to having a melanoma removed from my foot. I must watch my salt intake....sweets...too many carbs.....those immediately strike my feet and within hours I will find huge puss pockets. If i get sick...receive anesthesia or take a number of RA meds my feet will explode. I had a melanoma removed in December, 2017. It was hidden under a piece of callous and found only because the callous cracked at that area. It was stage 2b. My mom died from a melanoma that hid under her callous. After further testing it has been determined the chances of the melanoma returning in five years is 52%.....52% it will return to the same area..... when my feet hurt I am very frustrated and just dropping a pen on the floor makes me want to throw it out the windowt when the melanoma was removed I had a sentinel lymph node removed from my groin. I developed cellulitis because the germs from my callous traveled up...I was on antibiotics for seven weeks. FOr seven weeks my feet were fantastic...no puss...no water blisters....no cracks....no pain...and some callous actually decreased.....once i finished the meds within two days I had a puss pocket in the arch of my foot. I live for antibiotics. I also receive a full body shot of cortisone or my arthritis and that calms my feet for a few weeks as well.

Frank not known 1: Pain. 2: Ability to trim callous. 3: Lack of ability to be active for getting out of house and for better health. Just chores around house and going out. Even shopping for groceries. On good days you may be more active, but this causes more pain for next few days to get better. On bad days you hurt and can't do much. Every step hurts. In youth and adolescent years coverage was more evenly spread. Pretty much covering entire ball and heels of feet. With aging coverage becomes more localized at pressure points like medatarsal joints and friction areas. Sometimes seem to have more issues with nerve endings, and bundles, that last months. Then will diminish only to return later. My children and grandchildren's ability to deal with it. My own ability to to trim my feet is already causing me back problems. I've lived with it my whole life so I've learned to accept my limitations without too much depression, or frustration, just acceptance. Just wish there was a cure. Gene therapy, or something that make it go away. Would like to have information on contacts for sources that provide help with planning pregnancies for grandchildren to avoid passing the faulty genes on to their children.

Gail K16 The ability to walk and stand and get around N/A cannot do much on good days and even worse on bad days makes me depressed and miserable over the years

it just as got worse no they are there all the time going out to places and meeting people
depression just wish we could find a cure

Gary K16 Not being able to walk far without pain. Not being able to socialise Not
being able to play with my grandchildren in the garden / park As above really no
No Just the fact that I cannot walk far Yes - definately

George K16 Pain - this is always going to be top with me. when you live with constant pain for 50 odd years it affects everything you do or say Social - it has never been possible to just join mates and do things they take for granted. I have missed many opportunities I would have had without PC Caring - as I get older this has become a major concern. I have never ever relied on anyone but myself and I'm dreading the day when this happens I couldn't do any sport. I love music but missed so many gigs I would have wished to attend Job opportunities have been very limited Visiting places, like art galleries, going abroad, holidays going places with friends I can't walk 50m. It affects everything I do, even when the pain is low When pain is high it makes you bad tempered, you withdraw and you can shout at loved ones. PC costs money. always buying pain killers, equipment. finding suitable socks and I must buy 10 pairs of boots before I find one I can actually wear Its always been bad, but its even harder to walk now No. pretty much the same everyday. the level of pain can vary The pain. when its high it makes you feel like you will have a heart attack. Also, muscle wastage as it becomes more difficult to walk or stand I crawl a lot and worry about the affect on my knees Oh yes absolutely, it forms your personality. it makes you a liar or at least a storyteller to disguise so much. people, even family, don't understand so why bother trying to explain things It often causes you to think what's the point or why bother. frustration level is sometimes very high Concentration on tasks is sometimes difficult. I am bossy because of it, I want things doing and how I want them. I don't have the patience if things are done right it can make you shout or be sharp because its difficult to get off to sleep I am always tired I spend so much time daily trying to 'sort out' my feet. I miss time with my wife

Gladys K16 My boy is 8 years old, He has not experience all of the above but have seen his dad crawled out of bed or from one room to another to get a drink,, and that's what we worry is coming along the way, is a matter of how long ontill... He is 8 years old as any kid his age he will push till he can't started with the white gums and tongue, and after 3 years of age callus on feet anywhere where the shoe rubs from the heels to the toe area its just there, he is just to small to comprehend we have seen this from family members, Joint damage, back pain, unable to walk. He has hear his dad said how much he hates life, how miserable he is, the pain he is in. unable to enjoy family adventures, and the guilt we feel when he does. He is to little to feel any of this I am a caregiver of a 8 year old son with PC and Husband with PC, I remember going to the doctor with my husband, and listening to him beg the doctor to cut off his feet or kill the nerves and there is nothing I can do to help him to easy the pain away,

Graham K16 Hyperkeratosis on feet and hands. Blistering Cysts under the
hyperkeratosis Walking my dog. Playing sport. Being normal! Fed up with people

asking me why I walk with a limp. Sick of tending to my feet and hands. Sick of filing my nails.

More hyperkeratosis has formed. Occasional dreadful pain on my mouth and tongue.

Symptoms are always there. Always. Nothing improves my PC. Other people's reactions. PC gets me depressed. Sad to say my mother doesn't care at all. PC drives me mad. It drags me down. I'm sick of it. The dermatologists are paid good money, yet they achieve nothing! Nothing changes. 55 years of PC is dire. No cure in my lifetime is dreadful!

Gwen K16 1. Pain -can't enjoy walking in nature or for longer period of time 2. ugly toenails and calluses unsightly so hide as much as possible 3. Can't shower, must bathe. as pain too great to stand on hard shower floor Hike - see more of nature Play sports Wear high heel dress shoes for church and social events - impacts self image On best days symptoms don't affect me if I have taken painkiller (Excedrin) On worst days stay off feet and don't accomplish daily tasks Pain has increased as I can rarely find shoes that are comfortable anymore Toenails have curled up, gotten thicker and look uglier Symptoms are worse on hot days Taking over the counter pain medication (Excedrin) for 5 decades Not being able to trim my calluses as I age Frustration with not being able wear fashionable shoes or even buy comfortable ones Hotels are renovating and installing nice showers instead of tubs - frustrates me not to be able to shower without pain due to standing on hard surface, so start the day off angry that I can't enjoy the shower experience. 5 minutes tops is all I can stand. Grateful for PC Project that has made me far more comfortable talking about my condition, sharing about it with my doctors and not lying when asked why I am limping. Just grateful for PC Project for all the hard work to help PCers.

Heather K16 Calloused feet are the #1 due to chronic pain, hyperhidrosis, embarrassment, daily modifications and self care. Nails are 2nd as they are just recently started to show significant changes that are visible to all I'm a runner. But I'm limited to very expensive, specific shoes and limited running. I'd love to walk barefoot, but the pain isn't worth it. I'd love to wear a heel, but the sweating and pain make it nearly unbearable. I'd love to go to a pool/beach/hot tub/lake and not worry about what people think when they see the yellow "bird feet" or the macerated toes Best days-minimal. I won't let it. But I'm never pain free Worst days-I worry about my liver from all the ibuprofen! Only certain shoes work, sleeping is hard On my VERY worst days-when I see my 11 year old son painfully trying to walk, rather hobble across the hardwood floor after one of his sports practices. He sadly admits they hurt and asks for ibuprofen. When his friends first said (while at sport camp) "dude, what's wrong with your feet??!!" THOSE aware the worst days Feet have worsened, require more self care. Nails getting rapidly worse No How it will affect my affected son as he grows up All the above! But at the same time, I won't let it stop me. Mind over matter when pain allows. Here are people much less fortunate than I

Helaine K6c Pain that limits my activities Walking on uneven surfaces, in warm weather, Work that requires standing on my feet for long periods of time. Sports activities that I love, and I have to limit due to the pain On the best of days, I can deal with the pain--no problem. On the worst of days, I can't walk another step and have to sit. Consistently inconsistent. Some days good some days bad. Some times of day good (usually mornings) other

times of day bad (later in the afternoon and evening) Yes. What makes symptoms better--soaking in listerine every day, staying off my feet and banking my steps, keeping feet dry and cold. What makes them worse? walking on them, heat, friction, humidity, closed toe shoes.

It limits what I can do. Patience and tolerance for frustration--especially with the pain and the point of no return--when I'm out and the pain is so bad I just can't take another step.

It's hard but I know that my fellow PCers who have the other mutations, K6a K6b, K16, K17 have it much worse. I give them all the credit in the world for their courage and perseverance.

Holly K6a Pain when walking, pain when standing, pain when sleeping. Any kind of mobility activity - can't walk any distance at all; can't wear shoes for any length of time; can't participate in many family activities because of the pain. Best days - still need to limit my walking because of the pain. Worst days - blisters & calluses on feet are so sore, I can barely touch them, let alone stand or walk; any kind of pain meds available do not touch the severe pain, bleeding & deep itching. The older I get, the harder time I have in tolerating the continuous pain. I now find I can only ambulate with the use of a walker. Sores & calluses on feet seemed more tolerable when I was younger; maybe pushing through the pain was easier when I was younger. I seem to need more family assistance for all activities, the older I get.

My symptoms are fairly consistent. I know that any walking or standing will exacerbate my symptoms & worsen the blisters & calluses. If I can leave my shoes off & limit my walking, I know that my blisters will dry up some, which will ease the pain. My nails are consistently thick but when I accidentally bang them or cut them too short, they easily get infected, which is extremely painful. I've lived with PC for 68 years & know I'll probably see no changes/improvements in my lifetime. What worries me is that the younger PC patients may also see no improvements in their lifetime. For them to have to live with this kind of debilitating, constant pain is so sad. I know I could more easily live with PC if a more adequate pain relief (or numbing agent) were available. Suffering from PC pain is depressing; I try to not let it affect my mood, but I know it does. I'm quieter & withdrawn. Plus, I'm frustrated that I can't engage in regular activities. To have PC is frustrating to family (non-PC) members, too. They are always having to make allowances to accommodate me because of my limitations. If the pain didn't limit my walking, they wouldn't have to push me around in a wheelchair or forego activities because of me.

Ida K6a Pain Run Pain in feet Little The heat makes it worse Ability to walk. Depression, frustration, difficulties in some social settings

Ira K16 Pain Limited walking Limited activity Water activities Daily life revolves around the level of pain associated each day Has actually remained the same No. always present. Pain medication and soaking when becomes unbearable Not being able to care for feet (trimming) as I get older Days when there's greater pain may result in depression It is an extremely painful disease to live with

Jack K16 Limit my walking Limit my standing Spend quality time with family touring/walking Walking with clients to lunch On my best day, I can walk down a long city

block without thinking once about the pain. On my worst day, I simply refuse to walk. Period. Unfortunately, there are few best days. If I'm lucky, I get one per month. Most days I think about the pain with each and every step, including standing in place. My pain has gotten progressively worse every year, particularly in the last 20 years or so. I can see it in my walk and feel it in my bones. Symptoms are less if I limit walking. I treat the pain with hot water soaks, cold-water soaks, elevating my feet, rubbing creams, massage, Vaseline baths, Advil, and a lot bitching, mostly under my breath. I treat my PC by pairing down the calluses once a week trying to navigate those pesky blood vessels and nerve endings that get cut and inflamed in the process. Nothing really works. Future forward, I worry that my condition will worsen as I get older. The PC pain is constant and often makes me grouchy, sometimes to the point of lashing out to the people I love, work with, and even total strangers. I even think it contributes to my struggle with depression. PC changed my life, or better said, it IS my life. And because of its' enormous power, I respect it and have learned to live side-by-side with it. It's made me a stronger person and taught me how to be courageous by exposing it to doctors, strangers, and people who love me, not an easy task. It's taught me how to stand up to bullies who have no interest in learning anything about PC except as way to call me out as different. Good life lessons.

Jacqueline not known Pijn bij het loenen Schaamte door vreselijke teennageks en lelijke voeten Sport Winkeien Huishouding Moe Teleurgesteld No
Frustratie, moe en teleurgesteld om dingen niet te kunnen volhouden wat iemand anders wel kan

Jacqui K6b Limited ability to walk any distance. Difficulty with exercise and weight loss as it is too painful to walk or run I'd love to walk to work, or to enjoy a lovely day but I worry about how far I can get and how i will manage the rest of the day if I can no longer stand On my best days I can manage without anyone noticing. On my worst days I just want to cry because I cannot take another step or because I have yet another painful infected cyst My skin is much drier now that I am older. I cannot reach my heels to treat them as I once did Heat makes all the symptoms worse, as does humidity. Swimming helps, provided that I can get cream on my feet before they dry That I will be unable to afford the podiatry I need every 3 weeks just to be able to walk. It is okay now that I am working but it may need to be lessened once I retire I get frustrated when i cannot join in activities such as a long walk. This condition has affected my entire life. I had a promising athletic career when I was younger that had to be dropped because I could not stand the pain

James K17 constant pain in feet and hands would like to be more active with younger family members like play ball or just taking walks with family Best days I can work a few hours in the garage at work worst days I don't leave the house except to do desk job at work it has changed my appearance, early tooth decay and hair loss. a week at the beach seems to help, the salt water and soft sand. But I think it would help anyone. My hands seem to be getting worst, I have trouble just holding a pen in my hand. The skin on hands is callousing and splitting more often. I hope it doesn't get to the point of not using them well when my feet kill and I'm crawling at home it gets depressing just trying to do daily chores

James No Forms Cysts, Pain, Shame. I love walking and get restless standing still. I am fortunate enough to not have PC as bad as some others but I wish I were able to walk more than I am able to. I wish I can run. Sometimes my skin splits while swimming, and swimming is one of my favorite activities and I get depressed that I have to limit it. Some jobs where I have to stand/walk all day obviously have never worked out and I'd be accused of being lazy. Best days: I have ambient discomfort that is always present but I am just used to it as this point. When I think about it, my feet always hurt at least a little but It's not always necessarily debilitating. On my worst days, I'll have big postulating cysts on my skin which are extremely tender and embarrassing. These can sometimes be on my waistline and my belt-line rubs against it and it is nearly unbearable. If I walk too much (which can be while on vacation), I may have to take a full day to recover and soak my feet and I am not able to fully experience life as I like to. I LIKE to walk a lot. I LIKE to be active, but this is not always possible and I have to prepare ahead of time to have to sit out on some things. I have noticed more bumps on my skin as I get older and hairier as a 30 year old man. The calluses stay roughly the same. I feel that the bumps on my skin flair up if I eat a lot of unhealthy food and it usually happens at once. The only way I manage my PC is getting my calluses cut off with a scalpel by my foot doctor about once a month. Depression, irritability on painful days. Feeling alienated and insecure of my body. I feel that no one truly understands. I have been called lazy by employers before. Currently I am fortunate enough to have a job I enjoy that is mostly off my feet, but some of the biggest frustration came from people that don't understand the amount of pain I am in. The pain is less severe the less I am on my feet. But as I mentioned, I love walking and being active. Depression comes in when I am not able to fully experience activities that I enjoy.

James K6a Thus far, none of the symptoms have greatly impacted my Son's life. His Mom files down his nails with an electric file, and only rarely does my son have to limit his walking, although we do very carefully select his shoes and the type of soles that are best at limiting the effects / blisters. His Mom and I also put cream on the bumps on his body...these seem to come and go really, or shrink and swell. Sometimes they aren't too bad, and other times they seem to break out a little...but again, we manage well. As of yet, our son is unlimited. Plays soccer, spends long periods playing, etc. I'll only notice a limp in my Son's gait now and then, almost like a goose step for lack of a better word, and again, he does this very rarely. The bumps on his knees and body seem to come and go. The weather plays a role - as does his overall condition...if he catches a severe cold, the symptoms increase / bumps swell a bit.

The bumps on his knees and body seem to come and go. The weather plays a role - as does his overall condition...if he catches a severe cold, the symptoms increase / bumps swell a bit. He does not consume sweets very often at all...but if he eats a little too much, we sometimes notice the bumps increase. I worry that it will worsen as he grows, particularly on his feet. He is still only 3.5 years, and very active. So far this is not applicable. My son takes it in stride so far. One day he was about two and a half years old, he said "Mommy, I have dinosaur nails." We will continue to raise him to count all of his blessings and maintain a sense of humor, and to only allow him to be defined by his character and heart.

Jamie K17 The pain from my feet. Not being able to do anything. Activities or just laundry and showering is tough. The cyst make me sick and hurt as bad as my feet. I only have a couple days a month that I am clear of cyst. Emotionally challenging. Hard to have to depend on others for income and help. Yes I love to walk on the beach. Now I can't even stand in the sand without falling. Even with shoes. Best days I can get about 3 hours of walking or standing. Then worse days come after standing or walking for 3 hours. 2 days to recover Feet are becoming impossible to put weight on. Cyst keep coming. If I sit more than an hour without getting up I get cyst in my groin area. If I use my arms for rolling my wheelchair I get cyst under my breast and arms. If I stand my feet hurt. Cyst is in places no clothing can be worn until healed Come and goes but never stops hurting. Don't know what makes it any different. I cannot wear closed shoes or socks. Makes them hurt worse My child has PC and we are testing my grandchild. I hope for something to stop the cyst and pain of feet for myself but for them also Very frustrated. Hard to have a relationship with anyone because we lash out at people for the smallest thing It is a struggle. No one handles pain the same. I wonder how many people had PC and didn't make it to find out because of the self medicating. ?

Janet K16 pain limited mobility hiking, swimming, walking Best days, I can ambulate most of the day at 50% pain Worst days throw off my whole day, I don't feel up beat or feel like participating in laughing or smiling the older I got the more weight I have gained therefore the more my feet have been affected, the pain has gotten worse, unlike my teenage years. the pain can be at a reduced percentage but the symptoms NEVER "go". The fine line of moist vs too dry feet can make days more tolerable. Worse days are the day of or after I use a dremel to sand my feet. They are pretty tender after that. As I get older, it looks like I won't get to do some of the things I've always wanted to do. I just want to go on a hike, I'd like to walk in a park on the grass, simple everyday life plans have been "undone" and seems like I may not ever get to do these simple things. My mood makes me cranky! After a one hour trip in the grocery store, by the time I get home I can hardly stand on my feet as I get out of the car they hurt so bad. I often take it out on my husband, who is completely understanding but still, he doesn't deserve that. Of course I get frustrated as well in the winter when I have to put my one pair of shoes away because I either look ridiculous wear open toe sandals (with socks) when it's cold but the snow tends to get deep and everyone always want to know where my snow boots are. If I did manage to find a half way comfortable pair of snow boots, I could no way walk in them through a store or stand and pump gas. They could get me from the door at work to my car and then home. So not being able to switch shoes like most people make me sad PC is to me, emotionally draining to explain what it is to someone, if I chose to inform them. I have two Dr's, a podiatrist and my employer who is chiropractor that are the only providers in my life that know about "my feet" I just don't have the mental energy anymore to tell someone about them or show them pictures to help explain and have them say "ew" "oh gross" if they knew I have that condition I wouldn't hear the end of it. It's is a very limiting condition.

Jean K6a Pain pain pain These are the three worst things about PC. I can't walk very far, I restrict my husbands pleasure in that he loves to walk but he won't go without me.

Walking round lovely gardens, my husband has wheel me which is hard for him On the best days I can cope but on the bad days I get quite upset As a child I had blisters on my feet

and often had sores either side of my mouth. My Mum used to send me to school with plasters across the corners of my mouth! As I have got older the PC has improved a lot but maybe that is because I limit what I do and therefore this helps The symptoms are definitely made worse by doing a lot on my feet but there are days when I don't do much but they still hurt Pain As I have got older I have accepted the condition and i look at it like there are many people far worse off than me

Jeff K16 The pain after sitting for awhile after being active. The way that I walk, people wonder what is wrong. It is causing knee and hip issues. Walking around in the plant, hard to find comfortable steel toe shoes. Hang out in the pool. Unable to give plant tours. Wife doesn't like how much I twist when I walk some days. I have issues with ring worm and athletes foot Statins have slowed the growth down. Also using anti fungus medication has reduced them. Taking this because the fungus is impossible to kill under the calluses. I work at a desk job mostly, but good fitting, comfortable shoes help the most. Also, sock options are so much better now then they were. Being able to take care of them once I get older. it is frustrating not to be able walk without a "limp" or unusual. To think that you have passed this on to your child is a depressing thought. When I was in high school especially in gym class it was difficult and people would think that it could be contagious. Also. to realize that you have giving this to your child and that your grandchildren may also have this condition in the future is a burden that we bare.

Jo K6a Calluses on Flynn's feet, the pain of that and social activities Flynn loves and is obsessed with Soccer (football) and plays through the pain but is heartbroken that this may have to stop due to the pain. We live in New Zealand and have just come through the most humid of summers - his feet are in an awful mess and the pain and tears is hard on all. He has a wheelchair and crutches for those really hard days but fear that the crutches will cause blisters on his hands which he doesn't get - yet Yes. He plays soccer but one day it will just be too painful to play - he is gutted During winter it is like Flynn has nothing..... during the day that is..... but summer months are horrid. He loves PE and all sports and to just sit and watch his peers is heartbreaking I believe that as Flynn grows and gets heavier the condition worsens. Being such a long way away from anywhere sucks also Yes for the blisters/calluses and the plaque on his tongue. The bumps on his skin and thick nails don't come and go.... Heal balm is fab for Flynn's feet as is betadine. The pain says Flynn and the social "harsh words" - all I want to do is be normal Dear Flynn is a very sensitive soul. Don't think he knows what depression is yet..... we as his parents try and help him find the fun side of life. Flynn also lives with Haemophilia so using sharp objects as he is older will be super hard for him. Hoping for gene silencing or something like that and quickly.... You guys are super Uber amazing and I hope and pray every day for a miracle. A conference over this side of the world is a MUST also

John Paul K16 For sure pain has impacted my life from a young boy. As I got older I was forced to quit many of my favourite activities such as sports, ect. Embarrassment, social withdrawalment, suicidal thoughts, I've had them all, still do depending on the day/severity. The rarity of pc isn't good you feel all alone, no quote unquote professionals had ever seen or heard of it. Makes you feel crazy, like a freak, so humiliating. You can't hide it, it affects every

aspect of life. Physically, mentally, it's a real bitch. Walking in general. Something as seemingly natural as walking my dog is an excruciating endeavour. My wife would love it if I could go for walks with her... I could live On the best days I have to keep telling myself on more step... one more step... on the worst days I have to tell myself you aren't better off dead.... you are t better off dead... Gotten worse, more areas affected, more pain... Some days the degree of pain is less than others but never am I pain free... never..... That one day it will make my give up I suffer from depression, I have zero self esteem, I see my children suffer from it and I become overwhelmed with guilt. It makes you miserable. Too many

Johnny Junior K16 1. The pain in my hands and feet. 2. The callouses when they crack and open deep painful debilitating fissures. 3. The inability walk, stand, and use my hands for long period of time because of sweating, inflammation, and pain. Yes, I can not play or run with my oldest daughters for long periods of time. I can not visit parks or walk trails with my family and I can not play sports involving my hands like baseball, volleyball, tennis..ect. My symptoms on the best days, affect my life because I always have that moderate pain reminding me that I have a debilitating condition. I also have a problem meeting people or doing anything that has me using my hands. On the worse days everything hurts. I am irritable and my partner is burdened with my tasks as well as hers. They have progressively gotten worse. More of my hands and feet are covered and I can not play any of the sports that I used to play as a child nor can I walk barefooted as I did. The symptoms are always there but some days are better than others. What worreis me most about my condition is the in ability to work the jobs that I would like to, to the fulliest and how myself and my family will manage as I get older. I get frustrated a lot and take it out on those around me. I also feel embarassed and at times depressed. Sometimes that most pain comes from the medical professionals who don't understand the condition and have no interest in believing what I say about MY condition.

Jorge K6a Hiding my nails, embarresment. But mostly worried about how my daughter will feel when she grows up Some sports or water activities Not being able to walk properly Nails have gotten worse. Thicker and infected. Usually they are the same all the time but some days are worse than others. If i will be able to take care of my feet/nails when i grow older. A lot when having bad feet days.. get easily irritated and apathic.

Joshua K6a Painful callusses on feet limit activity level Too painful to walk None Best days nothing hurts. I can do normal activities. On my worst days I am unable to be on my feet Too painful Callusses on feet have gotten much thicker We noticed that symptoms are worse during hotter weather No worries No affect None

Julie K6a Nails and calouses on feet No Not particularlt. Not changed. Stays same.. Looks and discomfort with blisters. None Hope it doesnt continue with generacions, 1 daughter has pc but fortunately none of grandchildren do.

julie K16 The pain- my son experiences pain daily. His PC impacts his life in that it extremely limits what he can do. He is an active little boy and does his best but often, after he has been on his feet too much, he can't walk and has to crawl around from his bedroom to the

bathroom. He physically can't do all that he wants to and has to miss out on activities which his brother and friends do which causes him to get down. My son had to give up karate and tennis because they were too painful on his feet. He's had to stop playing other positions in football and now is the goalie (even this still hurts him). We can't go for family walks or runs and we have to plan everything to the hundredth degree to what we are going to do on holiday to the availability of parking nearby. PC has really affected our family life and what we can do together. It's horrible to see him limping and crawling when he comes inside after playing in the garden.

On his worst days when he comes out of school he sits down on the playground while we wait for his brother- he just can't stand up as his feet hurt too much. on his best days he can play outside or sports for a little bit but then the pain sets in and he has to stop. His PC had definitely grown worse over time. They don't really come and go. They are worse if he's been on them a lot or done lots of activities. He sees a chiropodist every three weeks to keep the calluses low and my husband also cuts them at times. This doesn't stop the pain though.

My heart is full of worries for my son although i don't let him know. I want him to stay positive. I worry about how is PC will limit him as he gets older- physically, socially and emotionally. I worry he won't be able to do what he loves (sports) and that he'll miss out on activities with his friends (he won't be able to walk around with them). I worry about him going to comprehensive school and uni as he will have to be on his feet so much more. He's a pretty positive little boy but at times he does get sad and frusturated with his feet. I've found him several times, just staring at his feet in frusturation. Even writing this brings a tear to my eye.

Thank you for looking into treatments. our family has gone past caring about how PC looks- it is unattractive but that's not the main thing- we only care about stopping the pain. I pray every day for a pain free life for my husband and son- so that they can get out of bed and put their feet down with no pain. Thank you.

Justin K17 The symptom that most impacts my daily life is the cysts. I can not be as physically active as I would like. I would like to be able to run track to improve my cardio health. Unfortunately, I am unable to run for substantial amounts of time without being in pain. Additionally, I enjoy swimming but remain self-conscious of the appearance of my nails and the bumps on my exposed skin. On my best day, I am able to adjust how I position my body so that the pain is reduced. However, on my worst day, I not only feel excruciating pain from the cysts, but I am additionally unable to focus in school and constantly worry about cysts erupting and draining through my clothes. Over time, post-puberty, my condition has worsened. I now get larger, more painful, and longer lasting cysts. My feet now begin to hurt sooner than they have before. This includes when I lay down or sit down. The cysts come and go and develop in different locations on my body. They tend to vary in size being as small as a pea to as large as a golf ball. I have noticed over the years that heat has exacerbated both cysts growth and feet pain. Because of this uncontrolled physiological response to the heat, heat has additionally affected my mood. I become less patient and more aggravated in the heat because my symptoms worsen. What worries me most about my condition is that I am more susceptible to potentially fatal infection (MRSA) because I constantly have open-abscess on my body. Additionally, as I grow older my condition seems to have more of an impact on my life. I fear this will impact my abilities to become an economically productive member of society.

As previously mentioned my condition worsens in high-temperatures. Subsequently, hot

climates or environments, impact my mood significantly. Furthermore, my symptoms make me feel self-conscious constantly. I always remain aware of how different my symptoms make me look. Living with PC is certainly miserable and impacts my life every day. Even though you may get over a feeling of pure isolation caused by such a rare condition, you never get over the physical pain it induces.

Kaitlin K6a Thick nails, calluses. No

karem K6a it was very difficult to get the weight increase when I was born because of the difficulty to feed it my daughter complains of pain while she sleeps that she can not carry out his activities normally

Karen K6b Foot pain when walking/running Walking, running & exercise Best days (ie: in winter/cold weather) - can manage symptoms Worst days (ie: summer/warm weather) - discomfort & pain prevents me from doing many physical activities No noticeable change Warm/humid weather makes my feet much worse That it's hereditary & my children have the same condition & theirs may also - and so on Frustration My two children have the same condition/symptoms

Karen K6a Appearance of callouses Pain of callouses Yes. Sometimes has to retire from sporting activities and take painkillers. Walks with limp. Has to crawl upstairs. Worsened. Slightly better in winter. Life-affecting, future jobs and activities. Gets very frustrated with oain, having to apply creams and seeing podiatrist. Gets anxious about fellow students noticing his condition. Even tho it is painful, he continues to run for hobby, gets good times and suffers the effects afterwards.

Karen K17 These answers are based on what my husband and son go through who both have this illness. The symptoms that affect my husband the most are the white cyst type lumps that he gets all over his body, they can be very painful, get very big, cause hair loss when he gets these in his head. He is also affected with the calluses on feet as this is painful running for too long Cysts are painful ,my son gets these on his bum and he complains about pain, they do not go unless my husband cuts in to the cysts and squeezes out the white fatty liquid It has gotten worse with time, more and more cysts appear and his feet are O'K once he removes the calluses but it comes back over and over again Using a razor to crape away skin on calluses eases pain for a while The severity of the cysts and pain he gets with these and also the calluses on his feet Frustration I care for my son and I see what he and his father go through on a daily basis. As of now my sons issues are mild due to his age but I know once he becomes a teenager this will get worse for him. My husband lives with pain everyday and I know when he gets these cysts in his head it is very frustrating and embarrassing for I'm as he looses his hair and then has to wait months for the bald spot to grow new hair. He will always wear a hat when this happens when outside of the house, he also has scarring all over the body from where he tries to remove the cysts.

Karina K6a The pain Play football , long walks with my kids and familie Run and exesiceNo effect at the best days , I can walk and stand longer. On the worst I only go to the sofa. It's much better Yes if I have walk long and the heat maked it worse. If my grand children can get it. And can my two girls that dont have it can there children get it. Not much I have learn to live with it.

Karmyn K16 Being 5, the largest effect on life due to PC has been difficulty walking somedays due to pain and not being able to participate in sports like other kids. Also, social/emotional issues due to actions of other kids. I would love for my 5 year old son to be able to fully participate in sporting activities or running around outside with friends. However, he oftentimes sits in front of a tv or with an iPod while his sibilings are active. On the best days, my 5 year old has very few limitations if any. On his worst days, he is unable to walk due to painful blisters and deep oozing fissures in his feet. As my son has gotten older, his PC symptoms (blisters, fissures, pain) have gotten worse. He is only 5 and is small for his age. I am hoping scientific breakthroughs occur quicker than he grows. My 5 year old does have variations in pain levels depending on the day--especially after having spent significant time on his feet. The fissures appear to be more painful than the blisters. My biggest worry is that my son's open wounds on his feet will get infected followed by social / emotional impact of being different and having limited mobility. My 5 year old has an amazingly upbeat personality. He loves life. On the rare days when he gets down, I know he is in extreme pain.

Kate K16 Painful blisters/ calluses and surrounding skin on the soles of my feet are the most significant problem. The pain is present to some degree all of the time, not just when walking/ standing. I trained as a veterinary surgeon, the physical demands clinical training was made very difficult due to the pain from PC. I worked as a clinical veterinary surgeon for two years, however my quality of life was too impacted by the PC pain and the physical demands of standing for extended periods prevented me from continuing this career path. I really struggled with the pain day to day, and ended up not being able to walk when I got home, and not able to enjoy my days off as I was recovering. I am now undertaking a desk based PhD as a direct consequence. I really enjoy being outdoors, and would love to be able to go walking including with friends/ family. This is not possible at all, I can go on some trips in a wheelchair or by bike but there are many areas that are not accessible to me. The best days only tend to occur when I have not walked much at all for at least a week, then I don't have so much trouble sleeping and I can walk around my home with only low level pain. On the worst days I cannot walk, and find it too painful to sit normally as I need to have my foot/ feet elevated. My condition has deteriorated over time, with larger areas of callus. Cooler temperatures and not walking/ standing make my symptoms better. There is also some waxing/ waning in discomfort/ pain which seems relatively random. Pain caused, preventing participation in activities I notice that when I am particularly painful I have anxiety problems. I also get much more tired when I am very painful.

KATHLEEN K6a Pain has the most significant, causing me not being able to walk far or for a long time I have tried different footwear but they are still the same. Little stones on pathways hurt and even the small ball on crossings for the blind hurt when walking over them. I am

quite lucky as I teach Body Pump and Spin but often suffer afterwards but I love teaching. I could do more in the gym field but I am limited with my feet, I love aerobics and dancing but even this hurts. On the best days they don't affect daily life. On a bad day it's just the pain I feel which gets me down. I think my condition has changed because I don't have as much skin on my feet but they hurt more, I can no longer wear nail varnish as this irritates and nails go septic. My fingers get cut at the ends causing discomfort. Every day is different my hand don't really bother me unless my fingers are split but my feet can be different some days to others, to make them better I find resting them helps and soaking them in salt water. The ability to walk and what effects it will have later in life on my joints etc because you put pressure on other parts to take the pain away from your feet. Definitely all off the above at some point I would say more frustration for me. Even though I struggle in everyday life I am not as bad as some of the people with PC.

Kathleen K6b nerve pain in calluses a lot of walking if I am not standing or walking for a long time and if I do not have nerve pain in calluses, I do pretty well. Yes. Worse-lots of walking and standing. Wearing shoes all day which makes my feet sweat and thus causes my feet to feel sore. Better-Wearing sandals indoors at home and whenever possible. Soaking my feet and using a "Ped Egg." Get off my feet and elevate legs. Being limited to what I can do. When in pain, it causes me to feel frustrated and impatient. I have often thought how people with healthy feet don't realize how lucky they are. The times when my feet feel pretty good I feel like I'm in Heaven!!

katie K16 embarrassment and feel need to hide feet from everyone wear nice shoes :) if i treat my feet and take them too low i may have pain during the night. if i leave my feet too long without treating them i will experience pain find it difficult to walk gotten worse.. more areas now have patches of dry skin yes some days worse than others my daughter will have it feel annoyed and frustrated at times i run on a regular basis and have completed a marathon and ran whole way so i am lucky that my pc does not affect me like others

Kerry K16 Feet pain. Hiking, watersports, and just standing barefoot Best days only limits barefoot ability, worst days every step very painful Gotten worse, Up till 15 or so could walk barefoot and participate in most sports Yes. No rhyme nor reason. Although heat generally worsens pain Losing shoes, and being unable to walk at all! Yes, although i view it from the inverse way. ie when the pain is least,,,,,i feel amazing in everything! Hard to explain the fluctuation of the pain, easy to hide, so mainly you do - and soldier on!

Kristi K6a 1. Painful calluses and blisters on my feet. 2. Painful nail infections. 3. Cyst getting infected Doing fun things outside with the family - like going on a hike, going to the zoo, going to an amusement park - or just anything that causes pain when walking - limiting what I can do with my family - I try and do the things i want so I don't miss out, it i do pay for it with worsening symptoms for days after Best Days - mild pain - allows me to be more active Worst Days - tend to stay at home and not do a lot with my family The cyst appeared in adolescence. The. All infections have gotten better but when I grind them down or injure them - the infections occurs. When I was working as a nurse in a hospital for 12-13 hours a day for 2-

4 days a week - my feet constantly had blisters, pain, calluses covering a lot of my feet. I have chose to take my nursing career and work as a nurse where it allows me to work from home.

Yes - how much pain I experience is directly related to how much walking or standing I do. Cold air helps. The ocean helps. Sitting down helps if I can sit down for at least an hour. I use Motrin when the pain becomes significant Not being able to do things with my family due to the pain I get frustrated when I attempt to do active things and the pain starts and it inhibits my family from continuing with the activity - like going to a park. I get frustrated that I have to depend on others to help when one of my kids need something and my feet hurt so bad that my husband has to do extra.

Launie K6a Foot pain Cutting off corns/ callus on feet ever other day Infected nails Any sport, travelling that includes walking, swimming, doing dishes (at parties/church functions), exercise that involves walking or jogging, dancing, running around with grandkids, walking on beach, barefoot Best days, not much if I don't do the aforementioned. Worst days, unable to leave the house for fear I cannot get home. Better. I don't do as much, less pain. I retired. If I don't move, it's can be fine. Broken legs help. Feet clear up. As mentioned, age may cause inflexibility resulting in an inability to care for my feet every other day. My tolerance for stupidity is about 0. Riding a scooter at Disneyland made me angry because of the way I was treated by other guests.

Laura K6b Pain - affects everything I do. Not just pain in feet, but get painful joints and muscles from my posture due to my feet. Its a lot to cope with every day, and constantly having to think what am i doing next and when do i have to stand up next etc. Embarrassment - ugly to look at and people are very prejudice. Restrictions on life - cant run any more, had to give up that and the gym. Have to plan events like weddings etc so i can plan where and when i can sit. Get high anxiety from having to constantly think about what im doing and can i cope with it.

Running and exercising. Used to be very important to me as a stress and anxiety release. Socialising - things like pub crawls, parties, gigs, fill me with dread On the best days i can put up with it, after having it for so long you get used to some level of constant pain and embarrassment and just live with it. On bad days i dont want to leave the house or do anything.

Gotten worse. Pain is a lot worse. Affecting my joints and muscles now too from the years of over compensating when i walk/stand Constant That itll keep getting progressively worse at a speed Definitely contributes to my anxiety. Does cause a lot of stress and depression too. My patience for other people is thin! Cant wait for that miracle cure !!

Laura K6a Feet pain because I am very limited in my abilities and cannot keep up with peers. Foot odor because it is embarrassing. Nails because people judge and look at you like you are a freak. Everyday life. I would love to do more chores but I am limited by pain. I would love to do more sports and exercise but limited by pain. On best days I have moderate pain and can go longer than usual. On the worst days, I cannot even walk for the simplest thing. Example, just walking to bathroom is painful or I have throbbing in my feet when sitting that are bright red from blood flow (i.e., hot foot). It seems to have gotten more painful and more odorous. I think it is related to higher temperatures and humidity of the

climate. They come and go. Heat and moisture makes it way worse. Cold temperatures are better and easier to go for longer in cold weather. The more I do, the more pain there is. The more I elevate the feet, the less pain. People accepting me with this pain and odor and ultimately limitations of being able to participate in life. Not too many folks that can hang on the couch all day because of pain. I feel inadequate and less than normal folks. I feel ashamed and embarrassed. That leads to depression and feelings of worthlessness. The pain is unimaginable at times. I wish there wasn't a stigma on ugly feet and an easier way to let people know about my limitations without fear of judgement or being left behind.

Leena K16 Pain, thickened nails, cracked skin Walking, running, dancing, travelling, enjoying nice shoes, walking barefoot Best days no effect, worst days restrict my steps. Impatience. Despair. Thanks to Neotigason my feet have become more flexible, after breast cancer medication parts of my callouses have disappeared. No using feet makes them better. Warm weather worse. Nothing worries me any more, I'm too old to worry.

I used to lack patience and feel an outsider. It also has forced me to think positively.

I never forget the disappointment when waking up and realising that meeting an other person like me was just a dream. (before pc project). I welcome dreams where I can run with 2 meter steps.

Lewis K16 Pain when I walk or run. No Very little on my best days. I am in a lot of pain. Not very much. No they are always there. Nothing At times I am a little in patience. No.

Lindsay K6a Thick callus and constant pain of the feet. Thick painful fingernails. A Portland OR based dermatologist removed my fingernails. I have little fingernails remaining on each finger. With less pain. Walking more than a mile without changing shoes or socks is often unbearable due to pain and blister growth. This hinders my life when I grocery shop, go to work, walk my dog, and etc. I am unable to do activities such as walk the Saturday market, go to amusement parks, and go hiking without intense foot pain and blister growth. If I choose to do such activities which is a normal amount of activity for a typical person of my age I have extreme foot pain for over a week while my blisters heal. On my best days I can go grocery shopping and walk my dog without extreme pain just slight discomfort and inflammation. On my worst days my feet are beet red covered in blisters and extremely inflamed. I can't even stand without extreme pain and discomfort. On these days I can't stand up to shower, let alone properly walk my dog or standing to cook and do dishes. When I was a child my conditions were basically limited to the white coating on the tongue, thick nails, the painful swelling and falling off the nails, and bumps on my waistline and thighs. Just before hitting puberty I got the calluses and blistering and inflammation of the feet and it has continued to worsen with age. I would estimate 40% of each of my feet including toes are covered in permanent callus and on average 20% of the rest of the surface is blistering on and off with friction of walking. The only section that stays pink flesh on my foot is the arch. With extreme blistering and inflammation that are arch will casually blister but not on a regular basis. My feet will be in better condition during the winter when there is less heat I have less inflammation and blistering. My calluses never go away but the blistering and inflammation occurs less in the winter with the same

amount of activity. I am actually able to do more activity in the winter. The pain of PC effects and worries me most. On days where my feet hurt so much I can barely stand I wonder how I can live another 40 years with this condition. I am 21 in 2 months, the days I can barely stand cuz my feet hurt so much are more often then days where I can actually go on a walk with my dog or actually walk through the grocery store without limping and putting my way on the shopping cart to get it off my feet. PC is a chronic pain condition so of course it comes with some forms of depression and anxiety about the pain. It's hard to not get emotional and tired when you want to do something but your feet hurt too much and you can't. I think I'm definitely more patient with slow-moving people in public because in my mind I'm thinking I don't know if they have a pain issue like arthritis or something. Where I think other people my age are just go go, and more impatiently and sometimes rudely storm around people through a doorway.

Linnea K16 Pain, it truly limits what I can or can't do. Social, it's difficult when you are limited as to what you can wear on your feet, or get stared because tou do wear what you want. People are worried you are contagious. Depression, wanting or needing to do something, or multiple things and having to limit yourself because of the pain that will occur and continue once it's over is mentally depressing and frustrating. I would like to walk at the park or in my yard more, but can't because my yard is lumpy and it hurts my feet just to walk in it. It is hard to care for my children when they can easily outrun me. I was finally able to get a job where I am sitting at a desk mostly, however I still end up limping around when I get home and am in horrific pain by the time I'm done making dinner. If I'm in too much pain we have to eat out which is expensive for us. It was hard as a teen who tried so hard to be normal and keep up with friends in activities. I've tried to take better care of myself. It feels like they've been more painful as I age, but maybe my tolerance is less. Mostly they are the same, however there can be good days and bad. I think the weather is part of it. The moisture in the air specifically. When winter hits and its really dry my callouses get really dry and cracked and my skin starts to kind of peel around the edgea. It will only get worse. What will happen when I get old? How can I care for someone else when I'm in pain. Usually get depressed because I can't do things and also because I gave it to my children, what have I limited them to be able to do?

Having a rare disease and explaining it ti someone else is difficult. Having to make up why you limp and feel embarrassed about stays with you your whole life. I can remember many points from childhood up I've had negative reactions to my feet.

Lisa K17 By far, the abscesses are the most difficult. I'm literally covered head to toe with small, medium and large cysts (golf ball sized). When they get infected(weekly) the pain is so intense that I can't get out of bed. The healing after incision and drainage is difficult and debilitating. I can't Walk or stand for more than 15 mins. The cyst spontaneously open and bleed or ooz pus with strong foul which stains clothing and bedding. Impacting social relationships Walk, running Always affects in some way. Best day would be minor pain. Worse day. Unable to get out of bed and need emergency room treatment as cysts grow aggressively About the same Incision of cysts helps That I will become disabled
Depression

Lorraine K16 Pain in my feet is the most impacting, because it restricts and overshadows what I do every day. Taking care of callouses has a huge impact, needing various types of care depending on my activity, and even depending on the weather. Cysts have a huge impact when they become inflamed or infected, needing to be lanced and having to take antibiotics. Day to day activities like cooking, cleaning, walking, showering, socialising are all restricted. My independence is greatly reduced due to pain impacting on what I can do each day. On the best days, I can do what I have to do, but still deal with a lot of pain. I would still not be near the level of ability as an "average" person. On the worst days, I am barely able to walk or stand, and spend a lot of time relying on help, occasionally unable to stay out of bed for the day. Gradually my symptoms increase. Over time I learn more ways to deal with upkeep, but the impact of pc still increases as symptoms practically never heal or reduce. Increases in heat or humidity make symptoms much worse for my feet, increasing pain, moisture, blistering, and increasing growth of callouses. More friction or pressure on my feet after or during more activity. Rest lets the pain calm a bit, and reduces the buildup of blisters over time, but I find that once a callous spreads it doesn't generally recede. How much it may worsen and spread over time. I can never know or anticipate how bad it will get as time goes on. It's very frustrating to be limited daily. Though I learned to accept it from a young age, it is impossible to not be affected by the pain and limitations that affect me on a daily basis. Some days I get on with things without affecting my mood, but especially if I'm going through a bad patch of pain, I can become upset, irritated and frustrated that nothing can be done to help.

Junghwa K6a I am Mom of 2-year-boy, PCer. He is just 13kg weight, so don't have serious problems on foot and palm. Just little calluses. But his thickened nails caused social interests, I need to prepare answers to people who ask about. Someday My boy will ask about his nails. I wish his different appearances don't affect his social relationship. Nothing special yet. I should trim his nails and toenails with little scissors before family days, etc. usually It take 1~2 hours. He don't like trimming by me. White things on tongue come and go. Usually it is small size so I don't care much. I dread pain he will suffer from. He likes running and dancing so much. I wonder until when he can do that activities with fear. He notices his nail different from other's but didn't ask about that yet. I hope he can accept his uniqueness as something natural. Anyway he is very happy, bouncy person overall. I aware about of rare diseases by my boy for the first time, and have chance to speculate what living with disability and different conditions means in our society. As he growing up, I hope I can be more sensible to diverse people, and can be a good friend.

Lydia K6a As a child I was made fun. People telling I have a fungus. No long walks or hiking. Feet get wet makes it hard to walk. Feet hurt so bad can't walk. I was on a couple of medical studies and the medicine I was given have lessen the callus on my feet. N/A At 66 I try not to worry about me but future generations. Get depressed because of limitations my feet cause.

Lynda K6b Unable to walk for any distance, would love to go for long walks on the beach. Or walk all day around a big quilt show! I am restricted on what sort of job I can do. Nail infections

can be very painful and stop me doing my hobbies Site seeing walking on holiday. Again walking around quilt shows. Just any walking in general that people take for granted, shopping, exercising etc. I have my life pretty much organized so that I don't walk too much, so on my best days it doesn't affect much. On my worst days if I have walked more than usual, just getting up out of a chair and walking to the bedroom, is more than i want to do sometimes

The calluses on my feet have become harder and bigger, and more difficult to trim down. My toes nails have become very distorted and will probably need surgery at some point

Hot weather makes my feet hurt more. Wearing shoes also. And of course walking for more than 20 minutes at any one time If it will get even worse over time Frustration at times I am lucky, I do not have extremely bad symptoms like some people with PC, and I suppose having had it all my life I am just used to it and the restrictions it puts on me.

MaÅgorzata K6a Painful blisters on my feet, that limit my live activities. As a young adult it's hard to find a part-time job, without standing and walking, and makes me dependent financially from my family. On the best days it's posibile for me to walk and stand for couple of hors, but on the worst days I have to stay at home, becouse of the pain. i think that they are in the same level. Most of my symptoms are the same, but I cut my nails, and go to podologist to remove part of my blisters and shape the rest and it decreases the level of pain.

Pain and problems with walking Sometimes afeel sand and frustrradet because of the PC, and my limits. Over the past few years I realize that for many people is hard to understand that I have good and bad days. A a result when I have a good day I try to not show it because when I have a bad day they call me a "liar".

Mark K6b Pain is the biggest issue for me. I take medication for the pain everyday I work. I try not to take it on the weekends as I know it is bad for my body long-term. Weekends I try to take it easy if I can so my feet will be rested and ready for another week of work. I would love to be able to go on walks with my fiancé. I try to do it when I can but offense pay for it later that day or the next. There are days where PC does not have a lot of impact on my life. I believe part of that to be true because I have grown used to limiting what I do to make it so. On my bad day all I want to do is sit down and get off my feet. That's not always possible life goes on and certain things need to be done sometimes. The pain makes me short tempered and hard to be around at times. When I was younger the pain wasn't as bad. I was able to play sports until about my sophomore year in high school. I wanted to play longer but I didn't want to deal with the it caused. Now that I'm older there seems to be more calluses and they seem to be harder. The nails on my hands have gotten a little thicker over time but still pass as somewhat normal. The nails on my feet are way past normal now and thick. Maybe once a month or so I seem to have a day where my feet feel great. I may take advantage of it and go for a walk or shoot some hoops in the driveway. After I will pay for it but it's nice to feel normal for a bit. Most days I have pain. The more I'm walking or on my feet the worse it gets. The only way to make it better is to get off my feet. Pain meds help but there are days where I feel like the meds aren't even helping with the pain. That the taking of pain medication long term may do damage to my liver or kidney. When I'm in pain my temper is short. I have little patience. All I want to do is get done with whatever it is I need to so I can get home and get off my feet.

My brother who is two years older than me and also has PC K6b. Played sports longer in

life than I did. He played baseball all through highschool and finally gave it up after two years in college because of PC. I can remember him crawling to the shower in the morning because his feet hurt so bad. He was always in a bad mood. Guys on the team would give him a hard time because he would walk funny. They had no idea of the amount of pain he was hiding just to play a sport that he loved.

Marlies K16 pain each day and night itch each night to wake up about five times each night All sports with using my feet (walking, runing, tennis, dance, skiing etc.) is not possible. Only to cycle and swimming in possible on my best days I can walk or stand about 30 minutes without pain but only with good shoes an insoles. On my worst days I cannot walk and I have pain when I am sitting or lying Now I am 69 years old. Problems began when I was 13 years old and got worse year by year. When I was 40 years old itching began and since I am 60 years old I cannot sleep well. My feet feel bad when the weather ist bad. Rain an storm ist not good. Atmospheric humidity, sultry, muggy, heat, thunderstorm and deep air pressure is horror. I never have bad mood. I am so thankful and happy because my daughter and my 2 grandchilds don` t have PC. I didn` t leave my PC to anybody. When I die PC is out of my family. That` s wonderful. I never ever met another person or doctor who knows PC. Nobody knows, what it means to live with PC. PC is in my mind every day.

Max K6a Blistering as it halts my ability to walk and socialise often and the discomfort can keep me up and it also stops me participating in a lot of activities , hyper keratosis as it often results in me hiding my skin a lot and can cause pain and infection in my nails as it can create pain and force me to use other things instead of a pen and paper which is an inconvenience and it can keep me up at night as well and can cause major discomfort. Performing as me feet hold me back from doing the dance ect. Best days: limping, nail infections occasionally and hyper keratosis acts up Worst days: major foot pain, hyper keratosis acts up badly, cannot walk at all, tongue can hurt Developed and more symptoms accuired such as hyper keratosis and coarse hair Th e hyper keratosis on my face and in my armpits comes and goes but it can only be helped with cold air such as a fan and no medication has helped with it so far Blistering as it stops me doing things I love such as going to public events Tolerance and apathy and usually very bright and cheery Often pc-ers are more embarrassed about their feet, nails and hyper kellatosis

Michael K16 I have to stay within my limitations concerning how long I am on my feet and how far I can walk at any one time. I can no longer run even if I had to. In general, walking must be accomplished on flat surfaces such as concrete or asphalt. Walking on grass presents problems with controlling the surface you cannot see well. Grass can be lumpy or have holes that you cannot readily see. On the best days, I can do pretty well between walking and be standing for periods of time. On the worst days, I have to limit the time I am on my feet. It can be an effort just to move around. I had problems with cracks in my heels that go all the way to the original skin beneath the callus. If I am not careful and trim the heels too low, those cracks become very painful to walk on and take days or weeks to get better. The symptoms can change with the weather. High humidity and rainy days are the worst. The skin becomes taut causing the skin to hurt even while stretching the feet. The skin feels like it will

crack open. These are the days that bedroom sheets and comforters become painful to the feet. Right now I am pre-diabetic. Having to trim my calluses every ten days can become problematic if my diabetes gets worse. I find that when my feet are really sore it sucks the energy out of my day. It makes me feel tired. When I was in 7th grade, I had a terrible itch in my one heel callus. The only way I could relieve the itch was by banging my shoe on the floor. When I got home that day I decided to cut into the callus. To my surprise, the cut I made caused about four ounces of water to pour all over my mom's rugs. I had a blister beneath the heel callus that broke when I cut into it. Then the strangest thing happened. I was able to peel the entire callus off of my heel revealing normal skin for the first time in my life. I was so excited I called my mom in work to tell her that I cured my heel. However, by the time I got off the phone, my heel was turning a dark red color and cracking everywhere with small surface cracks. At this point, I realized that this was not normal skin and I could not touch it to the floor. I had to construct a bandage so I could go to school the next day. The heel callus grew back but strangely did not grow out evenly. It actually started on one side of my foot and worked its way around to the other. I thought it would have grown out at all points but that didn't happen. This occurred over 51 years ago and never happened again!

Michele not known Not being able to stand or walk for long periods of time. And I believe all the sitting has affected my health. I also believe the mix of sitting and the unevenness the callous' create have caused my spinal problems. I love to explore nature. I cannot do that. My feet hurt, they blister, they Crack. I can't do anything involving chemicals, or even the simple task of lots of paperwork, my hands dry and Crack painfully. Doing anything too much causes cracks, callous and/or blisters. That restricts a LOT of things. I can't even go to the beach.

Since I avoid anything in life that can create the worst symptoms, I'd say it negativity affects life everyday in the worst kind of way. A kid born with no arms adapts to use his other body parts. My whole body is affected. There's no going around that. My hands have gotten worse with age. They Crack very easily now and on all fingers instead of just 2 or 4. Other places of my hands have started to dry and I'm afraid of what's coming. The surface area covered by my callous' on the soles of my feet has increased. The older I get the more painful it gets and the harder it becomes to do the chore of managing it. I.e: cutting it off and filing which can actually make everything worse if you do too much. No That I will become immobilized when I'm old. The health affects shortening my life. I can't move around like normal people. I tried water exercises but the chemicals in the pool were too much for my skin.

I don't know. I've always had this condition. I have nothing to compare to. As a child I was savagely made fun of by my cousins and friends. I hid it as best I could from then on. No swimming, no beach, no arts and crafts (though I did try) no musical instruments, the list is long. But I couldn't always hide it or avoid doing the things that made it worse. My grandma used to yell at me and sometimes spank me for having "boy" hands. Girls should have soft hands. I never did. My toenail became infected in second grade. It slowly started to Crack off. My brother stepped on my foot removing the remainder (the very top) and it was excruciating. Look, this hinders all aspects of life. You change how you do things and what you do. Everything. And there's no cure. The worst part? No doctor has ever been able to tell me what was wrong. I spent thousands on products in the hopes of getting better. I was 33 when I stumbled across a YouTube video that explained what was wrong with me. Back to the depression question.... When I was a kid I prayed EVERY SINGLE NIGHT for years and years to

wake up with normal feet. God never answered my prayer and it was very depressing. It was depressing that I couldn't show my feet and run in the sprinklers with my friends or go swimming etc. When I was 3 I remember walking down the road with no shoes and falling behind because it was too painful to keep up.

Michelle K17 Nails, cysts and blisters I'm not sure yet, the Patient is only 17 months old. In every day life the nails are very hard to manage and can become infected. It is very hard to trim them and my daughter hates it. The worst days are when nails or cysts become infected. We have had to get antibiotics for nails, cream for blisters on hands and my baby even had to stay in the hospital for 3 days on IV antibiotics due to cellulitis from an infected cyst. The condition has gotten worse. More symptoms have developed with age.

The nails are always the same and seem to actually grow thicker after being trimmed. Bleach baths seem to help with skin and nail flare ups/infections. Regular baths seem to help cysts as well. Have to keep the nails trimmed regularly about every couple weeks or they look worse and are more likely to become infected. The blisters on hands seem to come and go. The Mupirocin ointment seems to help on blisters and around infected nails at the base. This was prescribed by our pediatrician. Also antibiotics for infected nails or cysts help as well. I worry that my daughter is in pain and that she will be embarrassed and teased growing up. Mostly the pain though. My daughter definitely seems like she's in pain when she has flare ups or infections and she hates having her nails trimmed. She screams and cry's the whole time.

I would be so grateful for some good treatment options and hope that one day there will be a cure for the pain of this condition.

Miranda K6a Pain related to calluses on feet. Calluses & blisters on feet. Painful recovery if I overuse my feet (walking, running, etc) I like to exercise by running or taking longer, vigorous walks and that is not always possible for me. I also have two young children and I can't run on uneven surfaces like grass to play with them. On the best days I experience mild pain or discomfort in my average routine. On why worst days I can't comfortably walk short distances without excruciating discomfort. It's very discouraging and depressing. My symptoms have improved as I have aged and I attribute that to being more vigilant and responsible in the care and management of my calluses & nails. My nails also thinned drastically as I aged and are now hardly noticeable as atypical. The callusing has gotten worse on my feet My symptoms are pretty steadily the same. In hot weather my feet can feel more sensitive but the callusing actually looks better. In cold weather the pain can be less severe. I worry about getting older and not being able to comfortably reach my feet to maintain the calluses. I worry that the condition will worsen. It's very depressing to have a chronic condition that can only be maintained and not actually treated. Every time I have to take an hour out of my day to maintain my calluses I feel extremely agitated and mildly saddened that I have to deal with this burden for the rest of my life. The pain, comfort & embarrassment I feel are still very much a part of my life - but it was a hundred times worse during my adolescence. I would have loved to have been able to receive support or treatment during those years.

Nathalie K16 Do not make the sport that I want to do To explain the people the PC
Of course, running, playing hockey La maniÃ"re de marcher! Toujours devoir

expliquer aux autres notre mal et pourquoi on marche ainsi. La carte d handicap pour le parking m aide mais les gens me regardent bizarrement quand je sors de la voiture sans chaise roulante. Cette maladie est trop peu connue et c est dommage. No change since 30 years No its every day the same or maybe a little change with the MÃ©tÃ©o! Que les gens ne comprennent pas notre mal et nous regardent marcher d une maniÃ¨re..... Notting I still positive L histoire de la carte d handicap

Nikki K17 The cysts/constant abscesses affect my life so much I cannot work anymore. The pain is horrendous. Because of this my husband and I have had to change our life as there is only one wage coming in. This is ok for me but I worry of the affect in my husband who works full time, has to help me and look after the home. I have little/no confidence. I don't want to socialise because if the constant pain/issues with the suppurating abscesses. My family do not understand my condition and how it affects me physically and mentally and as such relationships are very strained. My one sister had breast cancer @ 7 years ago and she is still here thankfully and the family support her still. They do not know/want to try to help me so seem to avoid me and/or discussing the condition. My withdrawal socially is seen as a snub on them rather than results of my condition. I cannot hold down a job anymore because I am so unreliable. I would like to help animals but again the restrictions of my condition and my movements due to repeated abscesses limit me to home life. (I do know I am lucky that I have a home to be in) If any brief days where I have no debilitating and painful, disfiguring abscesses I try to walk in fresh air with my husband (I rarely go out alone). I miss our countryside walks that we did when I was younger and the abscesses weren't so persistent. I worry about lack of exercise and the worsening condition and as such the future. On the more common bad days/weeks I rarely leave the bedroom, trying to rest on the bed and trying to get comfortable with multiple abscesses (it is almost impossible) I'm tired all the time. Any unavoidable trips out exhaust me. New cysts are still forming and the abscesses are practically constant and usually multiple. When I was 8 (when condition first presented) I had perhaps 1 or 2 abscess a year. As I've gotten older these numbers have increased greatly just as the number of cysts have constantly increased and is say the abscesses are larger and can often lead to cellulitis. No The limits on my husband (he works so hard both at work and at home) and what the future holds. We rely on Employment support allowance of @ Â£100 a week that I am awarded to make up the shortfall as I cannot work . For this I have to endure a Fit for Work assessment @ every 2 years which is so embarrassing and distressing not to mention painful and debilitating. Mainly though I worry about our quality of life and my desperate fight to stay positive, for my husband and 26 year old daughter mainly I suffer from depression, extreme tiredness, feelings of frustration and aren't physically able/dont want to be sociable. I am angry too that my family cannot seem to understand the limits and affects of my condition and will not/cannot seem to make allowances. My mother has just a few stable skin cysts of the condition and as such does not understand the situation even though she saw it when I was younger It's he'll. In a nutshell. It's a constant fight every single minute of every single day to cope, deal with and not to give up

NykoleK17 Callouses, Cysts. It depends on what activity it is, and it's anything physical Just not being able to get up and be active or move around if there's a flare-up of boils.

And if feet are in pain not being able to stand up for short periods of time. From puberty to adulthood cysts/boils, and callouses increased. Haven't noticed I really try my hardest to not worry about it because in the past if I worried it would take me into deep depression that has brought suicidal thoughts. So I have learned over the years different things to do to keep me from worrying about it. Everyone who knows me and knows about the condition has often said that they did not know I was in pain or that they didn't know the condition was actually painful because I always have a smile no matter what and speak about it in a positive way, and that is due to the answer in question #17 about my answer of me learning to find ways to be encouraged through the symptoms on a day to day basis to keep from being in a deep depression state. It is a very painful, embarrassing, ugly condition.

Flinn K16 Pain Lack of an ability to live a normal life: can't go on walks with my wife and dog. Exercising, walking and standing are all limited based on how my feet feel at any given time. I have to "save" them for specific, pre planned activities Best days - no pain and I can live normally. Worst days - limited to the couch and my Crocs (the only shoe that helps). Disappoint my friends and family because they cannot comprehend the pain I have become more sedintary and gained weight which we believe increases the extent of my calluses. It's a downward spiral that makes me depressed I have no idea why some days I am pain free and other days it's unbearable. It's probably the biggest issue and creates lots of social problems
Passing it onto my future children. It hurts so much and it's horrible knowing they'll have a 50% chance of living a life of chronic pain It extremely frustrating and embarrassing. I'm starting to get past the embarrassment (mostly due to the fact that we now know what the disease is!) I constantly feel like a disappointment and am ashamed I can't do simple tasks

PAMELA K6a Pain and blisters Long walks, impossible to give without the help of crutches or wheelchairs On the best days, I try to do the activities that I can not on the worst days, like going shopping or going down to the park with the child. Yes, always with the help of my crutch I'm lucky, to be well treated in my hospital, so I'm better in time, although I still have bad days Cold! Right now, my baby understands that his mom has what she has and can not run much behind him. Actually, it is making it very easy for me and makes my days simpler than I thought it could be. My mood is very good in general. I have a lot of patience and a smile is always my ally on bad days.

Paolo K6a 1) Painful calluses/blisters on the soles of my feet 2) Infections in nails or feet 3) Painful calluses/blisters on hands Those three things together significantly have affected - because they limit or make impossible - my entire life in all its aspects: school/job, leisure activities & sports, social life, psychological implications etc. There are many, I'll just make a couple of considerations about my job as a pianist. On the worst days, PC prevents me from being able to perform at my very best. As a result, I have to carefully plan my studio sessions, alternate demanding pieces with simpler ones, allow for frequent breaks, and vary my technique. Also, promoting myself means a lot of walking and standing. When I have an appearance, I start getting ready at least two or three days in advance "stressing my feet only when necessary, inspecting venues online and asking for information in advance, and thinking of clever strategies to stay seated most of the time. Symptoms have a negative

impact everyday: depending on many factors, on the best days they limit my everyday life, on the worst the make it impossible. Yes, even if it's difficult to "measure" I clearly remember playing football when I was 10-14: it wasn't without consequences (pain and infections) but I could make it for short games (10-30 mins max). Another example: when I was 13-15 I could practice on the piano for 4-7 hours quite easily, now I can't do it for more than 2-3 hours everyday and I have to carefully plan my studio sessions as I said above. Symptoms are always there: 1) Not walking/standing, cold weather, less humidity, good shoes make them better 2) Walking/standing, hot weather, more humidity, bad shoes make them worse Pain, infections and their consequences (strong limitations, having to take antibiotics/pain relievers, impacts on my career as pianist etc.) Of course: especially when you're younger feeling that you can't do what "normal" people can do is frustrating and makes you feel really isolated; also you don't really feel like sharing, even more so when I was young because I barely knew about PC. Many people don't understand PC and even doctors sometimes makes you feel like someone who's complaining about a callus, "no big deal", someone inadequate, a whining person... I could go on and on. Over time you get used to everything and live your life according to your limits as much as you can. I'm aware, and keep repeating to myself, that I'm lucky after all both because there are diseases much worse than PC and because there are many people with more severe symptoms of PC itself. Nevertheless we all deal with our own problems and I have to admit that no day goes by without thinking about a cure for PC. Being able to spend more hours on my instrument, to visit a museum/church/city fully enjoying what I do, to do sports (swimming is the only one I do without bad consequences..) etc. would be really welcome. If not a cure, something to make the symptoms less severe.

Paul K16 Painful walking after a time No Worst days , difficulty walking especially on uneven surfaces No Days walking, worse uneven surfaces, worse Not a lot
No

Philip K6c I'm restricted in what I can do on my feet, this is quite variable and very temperature dependent, hot is bad, cold is good. Foot pain in unpleasant and restrictive in work and play. I need to ration my foot time for regular jobs, I know if I do too much today I will be able to do less tomorrow and pay for it in pain. I'm now retired but prior to that work was limited to fairly sedentary jobs. Dog walking, nature walks, dinghy sailing (immersion in water makes my feet very sore and they often take a day or two to recover). On the best days not much, as my 'normal' activity levels are lower than they should be. On the worst days any walking is painful and an effort and I try to avoid it as much as possible. I don't think the condition has changed but my life has adapted to what is possible with my feet. It was much more difficult as a teenager/young adult. Quite variable, good days, bad days, ditto weeks, sometimes without any explanation. But, heat and humidity is always bad, an increase in temperature will make my feet sore very quickly. Nothing Irritability on the bad days. For many years I was very reluctant to talk about it. It's a quite socially isolating condition, both because of the mobility restrictions and it's rarity and the difficulty of explaining or understanding it. Most doctors haven't heard of it and very few have seen it or understand it. This can be very problematic for patients when doctors think they're 'faking it'.

Polly K16 i feet get worse it is harder to care for the older it get playing with grandchildren feet HURT almost constantly calouses just get worse, move into new spots (i'm sure from shoe pressure) very dependant upon good shoes when pain is bad i have to cut calouses - harder to do as getting older no one will be able to assist in foot care - my son has same thing and might be able to help - but i have ALWAYS trimmed his feet frustrating when you feet hurt can be very debilitating at times

Rachel K6a My foot pain has the most impact. Painful blisters and calluses that get infected. I dream of going for a walk in the park near my house. Even just walking a few blocks with my husband would be amazing. I wish I could walk comfortably at work. On the best days I'm able to walk at work with minimal pain and when I get home I can still walk around my house. On my worst days I can't walk at work, I have to stay at my desk all day. When I get home I immediately drop to my knees and crawl. If it is a weekend I use my wheelchair or crutches if I have to leave the house. The amount of time I can stand or walk has decreased as I've gotten older. I have fewer infections, but in general the blisters take longer to heal. Heat and humidity make my symptoms worse. The more we stand or walk the worse the pain. Raising a family when it is so difficult for me to walk. I get really frustrated when I can't go out with friends or do an activity that everyone else is doing. I get anxiety when planning vacations because I worry about trying to sight see while not being in pain. I feel embarrassed when people stare at me because I walk "weird."

Randle K16 Pain in feet and hands. Heavy calluses on feet require hours of trimming, oiling to enable some minor comfort while walking. Calluses are constantly cracking, splitting causing undue pain and requires hours of time to bandage, repair. I cannot run, jog, hike and when really bad I can't walk on my feet. Best days about 15 minutes of upkeep and oiling. Worst days hour to hour and half trimming, sanding and oiling. On both my feet and hands the callus growth has expanded creating a worsening of the unkept and pain. No conditions are pretty consistent. Keeping my calluses trimmed and well oiled helps. Failing to keep calluses at bay definitely make the pain and discomfort worse. How will I be able to control it as I get older and less able to work on calluses. It pisses me off! Nope

Rebecca K16 Thickened fingernails, painful blood vessels under nails, painful, hard, thick calluses on feet I haven't allowed it to stop my participation, but it has always been painful for me to play soccer (through college) and coach my kids now, but I wonder how much better I'd have been without the pain. I don't know what it's like to walk or run without pain! On the best days, more moderate pain that I can ignore, although I cannot walk on hard floors indoors without wearing padded shoes or slippers. On the worst days, very painful toenails and deep cuts in the calluses on my feet that are excruciatingly painful. I can hardly walk on those days, but have mostly learned how to prevent and deal with those cuts so they happen less often. As I get older the calluses seem more brittle and build up and harden more and more quickly. My nails have also significantly worsened over time. The calluses are always there, just sometimes have more painful cracking and bleeding than others. Keeping them trimmed down helps, and keeping my feet taped with athletic tape minimizes the cracking. That it will worsen with age and limit my ability to be mobile and involved, and

eventually my ability to care for myself I think it has forced me to develop perseverance and the mental toughness to not allow the pain to limit my life. I have also developed increased empathy for others! It can be embarrassing and frustrating, but overall I think the adversity has been a positive force in my life. Thank you for listening and working towards a cure and tools to help manage the symptoms, especially for my daughter, who is five and also has PC.

Renee K16 Pain has the most significant impact on my life. The pain keeps me from participating in activities with my children, family and friends. The pain causes me to be much less social than I would like to be. Exercise is important to me, I do not get very much though, because it causes pain in my feet. Walking, going to the park with my children, jogging and running are some activities that I miss out on. On the best days I monitor my activity and make sure that I am not overly active. On my worst days I sit on the couch with nothing touching my feet so the pain is less. The average person takes 10,000 steps a day, on my BEST days, my average steps per day with PC are 3,500. Over time I have gotten more calluses and they are larger and get deep fissure type cracks that are excruciatingly painful with ANY pressure on them. My symptoms are present on my feet at all times. The pain is always present as are the calluses. Not being active is the only thing that makes things a little better for my feet, but much worse for the personal life. Being on my feet for long periods of time makes everything worse. Standing or walking will make pain worse. The calluses on my hands will come as I use my hands more and will lessen when I work with my hands less. They are still always present on my hands, but will diminish in size with much less use. I worry most that I will not be able to care for my feet when I am older. I am short fused on the days that my feet are at maximum pain. I get depressed when I think about all that I am missing out on because of my feet. I cried on both days that I learned my two daughters also have this painful disease. Living with PC means pain every single day. PC pain will wake me up at night. There is a constant burning pins and needles stabbing feeling in my feet when I am resting. When I am standing the pain is more intense like walking on rocks and broken glass. Living with PC means people asking why you are limping. Why do you always wear running shoes even when you are wearing a dress. Living with PC is your children no longer asking if they can go to the park but instead having them tell you that "We cannot go to the park because your feet hurt today right?" PC is painful and embarrassing. PC limits my potential and makes my life so much more difficult because very few people understand what I am going through.

Richard K16 The pain associated with PC has the most impact on my life. I guess that the physical appearance of my thickened fingernails also has a big impact. Finally, the callouses on my feet, and to a lesser degree on my hands, limit my participation in summer activities. Swimming in public, although I now wear water shoes. Walking with my wife is very limited. Since I have retired, there are no better or worse days. I have settled into a life where my pain is not as severe as it was when I was working. Definitely less pain than before retirement. Symptoms/conditions have not changed much over time. Pain is less because I am on my feet a lot less than I was when I was working. Pain is always with me. It does come and go to some extent depending on activity levels. I worry that I won't be able to look after my feet as I get older. I have learned to live with my condition, so I guess that a certain apathy has set in. It certainly was good to find out that PC is an actual diagnosed condition. As I

child, I could never understand why I, and my siblings, were 'blessed' with our callouses, thick fingernails, etc.

Robbyn K17 Pain, inability to work, inability to walk My work and travel plus keeping in shape and active. Some weeks I can't walk at all Best days- minimal impact - won't go hiking or do high impact sports Worst- bed ridden in constant pain It's progressed over time and cysts have increased with time in number and pain Better- Botox in feet, ice packs, keeping them trimmed Worse- dry weather, big changes in atmospheric pressure and weather, fluctuations in hormones (menstruation and ovulation), high impact sports, really hot weather, closed shoes That I won't be able to work. And that I won't be able to walk or be able to look after kids Makes me frustrated and depressed at times (when bed ridden). Otherwise mood is okay Botox has helped a ton- targeting hyperhidrosis Going to look into surgery to cut off sweat glands to feet

Robert K6a Pain, blisters and callouses have been a constant. The appearance of my nails caused me embarrassment until I didn't care anymore. Not really. I don't let this stop me from anything. On the best days, I don't notice my pain. On the worst days, it forces you to slow down and find any opportunity to get off your feet and make you desire nothing more than to get home and put the feet up. There was a point when I used Accutane when I noticed a great improvement. I believe there was a lasting affect in my feet that coincided with job change. But there are still blisters and callouses, but during the accutane, it cleared out old, historic callous that never went away in my life. It was more like a reset that got rid of 20 years of damage and allowed me to start anew. It still hurts, but really not as bad. Heat, humidity make things worse. Summers can suck Nothing. My son lost his life with an overdose. He was born with my condition and became addicted to opioids while seeking to relieve his pain. You really don't want to know how badly this disease has affected my mood Other than my son's death, no.

Robert K17 Pain in walking. Cysts all over my body Pain when standing any length of time. I go just go for a walk in the country, as its to painful. I can't take part in any fitness exercises as its painful I'm in pain from the moment I step out of bed, putting my feet to the floor to when I get back in bed. More pain in my feet, more cysts over my body, nails on feet have been recovered to help with foot wear. Finger nails still get infected from time to time. Pain level is dependent on amount of walking I have to do. If my fingers nails feel like they are getting infected I dip them in boiling water for as long as possible, this does appear to help At some point I might lose my job due to time off because of PC. Sometimes I get depressed about it, but I have had it all my life now and have come to terms with it now. The pain is the worse thing. The older I get the less I care about people staring at me. I used to as a youngest keep covered up. Not any more.

Robert K6a blistering of feet calluses on soles of feet walk and stand dependent on pain killers difficulty walking nails no longer become infected hands and fingertips are not as blistered not as many cysts become infected. rest and elevating my legs and feet is best. humidity makes the symptoms worse collateral effect of daily doses of

Excedrin on my organs. infections. I become very quiet and withdrawn when in pain. My tolerance for pain and stress can diminish over time. having PC inherited was not an option for me. I delayed becoming married til I was 38. we chose to adopt a child rather than take a risk of passing PC on to a child.

Roseann K6a Pain, sleep and quality of life What the average person takes for granted, i.e, sleeping, standing in shower, doing spontaneous things so I don't have to pre plan everything all the time Sheer utter exhaustion on the best and worst of days. As a 51 year old female, PC has presented differently through childhood (blisters on hands and feet, bumps on friction points), puberty where bumps and blisters started to subside, 20's - 30's blisters became smaller harden calluses on hands and feet where nerves started to expose & painful cysts grew on back and groin No, pain and symptoms always present Being such a burden to those I love and who love me and not being able to care for myself as i get older. Yes, exhausted all the time, feeling like such a burden make me depressed I know there are far worse things in life and we are blessed this is not life threatening, but the constant pain sucks!

Roxanne K6a I don't have children and have actively tried my entire life to not bear children due to the hereditary nature of my disorder. It is depressing and makes me feel quite sad that I really don't have a choice in the matter. I enjoy a variety of sports, but things like playing ball sports, running, rock climbing, bowling, anything to do with finger nails needing to be trimmed are all things I cannot do. If I want to partake in activities with others, like yoga or dance classes, many times you are barefooted and this is embarrassing and painful. The misunderstanding of the disease causes people to think that you are dirty or can cause infect other people. I also use my hands in my daily work and I feel really embarrassed when people cannot focus on the product/work at hand and literally cannot stop staring or asking about my nails. I feel like I have not tried to look for other jobs where I work with other people because the ones I work with now are accepting and kind. In other organizations, I would have to start over in gaining respect and trust and educating others about my disorder. Even something as simple as cooking or showing someone a technique, they get scared my fingernails are dirty and there for the food I make is contaminated, so I often wear nitrile gloves if I'm doing any cooking for others. I don't have as many nail infections because they bruise and bleed vs getting infected and falling off. The leukokeratosis has seemingly gotten worse overall, causing soreness when eating or after, with the exception of times when I have a really strict diet and can visibly see my tongue with less whitened thickness. The leukokeratosis lessens when I have a really strict diet of vegetables/ cruciferous greens and refrain from any dairy/soy/alcohol, coffee/sugar. I can visibly see my tongue with less whitened thickness and the sides of my tongue are not as scalloped. Unfortunately, my mouth does its own thing at night so I have found bite marks and wake with sore tongue due to my mouth being small and the oral mucosa overtaking the space in my mouth. I don't have children so I don't have to pass this onto my children. It will be disappointing when I cannot walk without pain when I get older. I foresee gaining weight and depression if I cannot exercise. I am a pretty angry and emotional person most of the time. I have a high pain threshold but it isn't a positive thing. I feel like I always have to hide something. PC wastes time; I have only so much time in a day,

but a lot is spent trying to figure out how to hide, maintain/ work around and manage pain and PC. I had a friend who quit smoking because he said he found that he was wasting hours in a day on an addiction/habit. PC is not a habit we can leave, and it seems that it's a lifelong ritual all of us would wish stopped stealing our time on earth. I wish my other PC patients hope for their future kids and this support group has at least given me perspective on the goals many of us have made while living with PC. However, there are many whose lives were stolen from PC and the unfairness of it all is quite depressing.

Ruben K16 Constant pain and discomfort. Limited mobility. Depression from not being able to live a normal healthy life. Walking and standing for long periods of time. Like going for a walk at the park, or attending a concert. Playing sports. Having to plan every step literally, always being mindful of the distance and duration I will have to do. On the worst days, not being able to walk from the extremely painful calluses on my feet. Feeling depressed about my condition. Not being able to go out and enjoy life. The pain is constant and fluctuates daily. Everyday activities like going to the bathroom are dreadful painful steps. Each step hurts. Having to always be laying down or sitting down. Weight gain. Anxiety. I've gotten new calluses on both feet. and some of the old ones have become bigger. My ability to walk or stand has been drastically reduced. The pain is stronger at times. Certain weather causes more pain than others. Not getting restful sleep because of having to place feet in a somewhat comfortable position to limit pain and discomfort. Feelings of depression and anxiety. Feeling apathy and anger. They don't really come and go. But limiting walking helps. That it will get worse and being fully disabled and having to use a mobility device. Being homeless from not being able to work and Social Security Disability case being rejected. My children inheriting this debilitating disorder. It has affected my mood in such a way that I feel depressed most of the time. Feelings of apathy. Have become more reclusive. Almost anti-social. Limited patience. Outbursts of anger. Frustration of not being able to participate in everyday activities. I have not received my lab results as of yet to officially confirm that I have PC. But living with the symptoms of PC all my life, I know I have it. The amount of pain one goes through is unbearable at times. Make PC more well known amongst doctors and health care professionals. It's an ultra rare genetic disorder that needs to be taken seriously. There are many people suffering with no hope for a cure or future.

rylee K6a pain yes can't move yes gotten worse no, also vey bad getting worse yes no

Sabina K6a calluses - because of the limited and painful walking, not being able to perform different activities, thickened nails - self-esteem problems i would love to be able hike, dance and run i end up in my bed for the rest of the day, with a feeling of depression physically they remained kinda same but psychologically they have built tons of limitations heat makes my symptoms worse and cold make them better that one day i wont be able to take care of myself anymore it developed a lot of different moods and conditions which i guess on long term shaped also my personality no

Sachiko K6a Calluses and blisters are painful, cracking and itching, nails cause kids to ask questions or look at me I play soccer and basketball and feet are sore afterwards Best days I focus on positives, great friends, great family, happy life...worst days I crawl on my knees bc it's painful to walk and I soak More callouses mor blisters less fingernail infection
Activity makes worse Getting worse Sometimes frustration My sister has PC as well, I'm 12 and she's 14. In that sense we are able to support each other emotionally. No one else in our family has it or show signs of it.

Sandra K17 As a baby my throat swelled to the point I had difficulty breathing. Wausau Wisconsin hospital used radiation and the swelling subsided. Last year I developed breast cancer. Over my adult life a large number of inflamed cysts were removed from my under arms(needing plastic surgery) and my peri area. Their pain was severe with major inflammation making it difficult to function. Currently I have this problem again. It may be from anti estrogen meds. Over my life, when I was pregnant the cysts became, fewer, smaller and did not become inflamed. When a young child, the bottoms of my feet sometimes hurt on uneven surfaces and their pain would wake me in the night. When I have inflamed cysts I am usually flat in bed with a heating pad. It effects my energy level and my thinking ability. As a baby I almost died from my throat closing. During childhood the bottoms of my feet hurt. From start of menses to pregnancies all was calm. My OBGYN kept me on birth control pills to control the cysts until menopause. Occasionally a cyst would need surgery. Recently when I had breast cancer surgery and was started on 3 different bouts of anti estrogen meds. The last antiestrogen med caused my cysts became bigger, deeper and the inflammation extreme. My Nails are starting to crack and periodically the bottoms of my feet. I have just recently gone off of the anti estrogen meds because of an increase of PC symptoms plus many other side effects. I think there is an estrogen connection. See previous answer That it will worsen like it had started to when on anti estrogen meds. Depression, exhaustion brain fog

Satvik K17 As my son age is only 1.5 hrs, He could not express the pain. But nail thickening is severe as far as my perception and recently a blister is formed in right leg where he is experiencing pain. More ever he will be struggling with pain in legs during his sleep. As a small kid he loves to run and play, but some times he feels pain and get dull and frustrated equally when he is not able to do it. As a small kid, he cannot express So, far it is getting severe over the time. Yes, we could see some blisters on and off under the foot. Only pain is the worrying factor, irrespective of nail deformation and other physical features. As long as my kid is free from pain and able to do his activities of playing. Atleast childhood should be free from pain is my expectation. NA My son is only 1.5 yrs, We came to know that he has PC when he was 1 year old. we are very depressed by seeing some pics in google. We could not imagine why is this for a small kid. The most worrying factor is that there is no treatment. Me and my wife cried a lot. I spent months reading articles for any treatment, If available. I strongly feel that PC project will find some treatment for PC and relieve the pain for all the PC patients across the globe. I sincerely urge all the great scientists working for PC to find some treatment.

Selena K17 The calluses and itching in Naomi's feet makes her ask to be carried more than other children her age that are working at becoming more independent. The emotional tug-of-

war she experiences between seeking independence and giving in to her painful feet also makes her irritable at times. The areas where she has a lot of follicular hyperkeratosis are easily irritated and painful. They can also become infected. Baths with epsom salt have improved the appearance of these areas, but they haven't completely resolved. We spend time each week sanding all 20 of her nails with a Dremel tool. The nail tissue that is left splits easily after it gets wet making her nails sore and making another avenue for infection. I use nail polish more for the purpose of sealing the nail than to improve the appearance. We live on the edge of the Great Smoky Mountains National Park. My husband and I both love to hike, but we haven't done a hike longer than 1 mile in years because we know that we will spend part of that hike carrying Naomi. So far we have been able to find ways of doing the other things we enjoy as a family using strollers and planning ahead for more time, frequent breaks and shorter routes.

On the best days, very little. She might bump her fingernail on something and say it's sore, but she tends to just ignore it and go on. She may play all day with out pain. She cannot pick up flat objects, such as coins, from a table or floor even on her best days. This is because of the shape and thickness of her nails. On the worst days, she will repeatedly ask me to scratch her feet, and ask for a bath 3-4 times throughout the day, as the soaking seems to make everything feel better. She will also demand to be carried even short distances rather than walk. I avoid leaving the house on those days. When I go to work, my family watches her and they also will keep her at home. For Naomi's first 9 months or so, her nails and 5 natal teeth were her primary symptoms. She had some small cysts under the skin but they were not inflamed. Her lower middle incisors are 2 of the teeth she was born with. They were small and floppy, but with a calcified edge on top. This rubbed against the underside of her tongue as she was learning to nurse (breastfed babies stick out their tongue when nursing correctly), and made it uncomfortable for her and me until she got used to it. She needed supplemental bottles for about a week. When she began crawling, she developed areas of follicular hyperkeratosis on her knees, and that has remained her most prevalent and painful symptom for the last 3 years. The plantar calluses have developed over the last year and the itching is more recent, maybe the last 2 months. So far, managing the nails and "bumps" require the most attention, but the feet are gradually gaining. Her 5 natal teeth fell out about a year ago. They were all lower teeth, and never useful. So now she has 2 incisors, 2 canines, and only 1 molar on the bottom. She cannot bite or chew hard foods like raw carrots, or tougher foods like pork chops. Her food choices and feeding have always had to be modified. The number and irritation of the follicular hyperkeratoses varies. We have had the most improvement using epsom salt baths and Vaseline's "healthy hands, stronger nails with keratin" lotion all over. Heat and dry skin makes it worse. We let Naomi be picky about her shoes. If she says her shoes hurt, we change them. I believe that doing so has kept the calluses to a minimum. The limitations on activity and career choices Naomi will face because of the pain. It's hard for me to speak for my almost 4 year old about how this has affected her emotionally. I know that she is more irritable on the days that she needs more help (being carried, soaks in the tub). But she is only just beginning to grasp that she is different from the rest of our family in a way that is not something to celebrate, as most differences between individuals would be. I'm not sure how smooth or bumpy this road is going to be for her. I need to stress the essential role that PC Project has in our lives. They have been our source for accurate information, emotional support, definitive diagnosis, treatment/management ideas, and HOPE. I think anyone who

faces a diagnosis that doesn't also have a cure, deals with feeling helpless and powerless. Those feelings have their own pathology, as anyone who deals with chronic conditions will know. PC Project and its work goes a long way towards restoring the feeling that something can be done and we are not powerless. The importance of that should not be overlooked. I love the doctors that work with Naomi and our family. They are skilled and caring people. But the rare nature of this disease means that within a few short weeks, I (as her mother) was the expert in the group, not the doctors. And not because I am trained in any particular way to assume this role. I'm just the one who loves this little girl the most and who is the most involved with the minute to minute reality of her disease. As Naomi grows up, she will surpass both her doctors and myself in the roll of expert in her disease. Without the people in PC Project, imagine how terrible and lonely this position would be. As much as I long for a cure for all rare diseases, I also have a fervent hope that involvement with a quality patient support group will be a reality for each and every person affected by these diseases that are isolating by their very nature. I am thankful every day that PC Project entered our lives early in our journey.

Sergio K16 3 Run, to walk, to go Beach. Now not too much Too much Yes
Sometimes bad other not. Seeing other people with normal Uf I have much.

Sheri K16 PC limits your ability to be on your feet...period... for any length of time in any shoe no matter how comfortable the shoe appears. The pain is debilitating and affects all parts of life. Remain active, exercise, work, go on vacation like a normal person, dress, swim, run, ride a bike..everything every single part of every single day is affected by PC. It's completely invasive every moment of every day. Getting up in the morning to night time. On my best days, I have severe pain and sit a lot. On my worst days, I have severe debilitating pain and sit a lot.

I have always worked and the walking and the dress code has always been a big problem, and when I was self employed, the constant workload is just unbelievable torture.

No. One thing that is constant is pain. My children didn't get it, so nothing now that I'm in my late 50's. Pain affects all parts of your daily mood. Not being able to do what needs to get done is always a struggle. No

Shirley K16 Pain. Embarrassment. Worry about condition worsening. Would really like to be able to walk the dog longer and go on longer walks with my husband. Worse days. Trying to hide my nails and compensate for some limping. Best days. Lesser degrees of the above or less social interaction. They have actually become easier to live with. If cracks are not addressed immediately, they are harder to fix. The fear of not being able to walk. All of the above. But try to not let it have too great of a role in my life or take on too much importance. No

Srinivasan K16 Pain and inability to lead a normal life as others has had the biggest impact in my life. Socially I believe that I am unsuited because of the ugly manifestation in my feet and also the way in which i walk. I love travelling places and this has been one of my biggest regrets in my life because of PC Pain is the biggest impacting factor as far as my daily life is concerned. Some days it is manageable but most of the days it is excruciating.

Pain and the toughness of calluses have worsend over years. Pain keeps changing

every now and then. It might worsen with age and I also will have to live a withdrawn and socially shameful life. Yes, it has. At times I do feel frustrated and impatient especially when I have to do things standing or walking.

Stacey K6a Painful calluses and blisters on my feet impact my life daily due to varying daily pain. Leukokeratosis also creates some discomfort and irritation in my mouth, and is embarrassing more often than not. My nails also grow at different thicknesses which causes a lot of discoloration which is embarrassing, and sometimes they get infections which are extremely painful. I love yoga but am unable to practice as often as I would like due to my feet. I also love outdoor activities but have to severely limit them due to the extreme pain that can last for days after the activity. On my best days on a scale of 0-10 in pain (0 being no pain) I average out around a 4-5. On my worst days I wake up and stay at a 9-10, and sometimes I am unable to put on shoes or even sleep due to the intense and constant pain.

My symptoms have been fairly steady over time, though I have developed more cyst like symptoms over the last 10 years. The pain comes and goes depending on my activity level, the weather, and other outlying factors. Pain medication works to a point, and depending on what I am dealing with there are several different ways to improve my symptoms. For blisters, I find that soaking my feet in warm salt water helps dry them out. For cracks, I use A&D ointment with a sock. Air is good for healing, as is sunlight to a point. I worry that as I get older my condition will further limit my mobility. I also worry that as I get older I will be unable to take care of my feet and will have to figure out what to do as I go. I get anxious if I know my feet will be exposed at any point. I get frustrated when my condition prevents me from doing what I want to do, and become depressed if the condition does not heal for an extended period of time. I also hate explaining my situation to people, and find it provokes my anxiety and causes me mental distress. Having a condition that is unknown and not understood is scary. I have had to google myself with doctors, and have had friends google me without my permission to figure out what's "wrong" with me. On the one hand it's nice to have their support and understanding, but it is terrifying to know that they can know my personal struggles with a few random google searches. I have to plan my life around my condition, everything from what I wear to my daily activity levels and even my week's schedule must adhere to however I seem to feel when I wake up.

Stephanie not known I have found ways to mask my PC symptoms by wearing false nails (both hands and feet) and years of maintaining the problems but it's hard when my nails aren't filed and are noticeable that I realize that people notice. No It's more of a cosmetic impact. They no longer limit me. Once my body hair stopped coming in, I no longer have the bumps all over my legs. Now they look like freckles. I also no longer suffer from blisters on my feet (although that might be because I stopped dancing). No. I wish. How will I manage it when I am old and unable to bend or if need chemotherapy and its affect on nails. As I am older, it makes me depressed because I am tired of having to maintain the condition or having to do a ton of cosmetic work before I go to the beach or pool.

Stephen K6a Pain especially when trying to be "normally" active I would like to be more physically active, but the pain at the time of activity limits me, and the fear of the pain

that is to come after limits me. I'm able to keep up with my kids I have to sit while they are off running around More nucleated calluses which are very painful points in my feet. Change of seasons seems to cause more pain Not really any worries - nothing I can do about it Sometimes frustrated that the pain causes me to slow down or just sit

Stephen K6a The pain impacts me every day especially the first couple hours when I can barely walk. This limits my job performance and abilities. I also spend about an hour a day grooming my feet. If I don't keep my calluses trimmed, then wearing shoes becomes even more painful. I would like to spend time going places with my children, but I am limited to activities that keep me off my feet. I also feel that my overall health suffers from my lack of mobility. On my best days, I still have to restrict my walking, which causes me to miss out on physical activities with family and friends. On my worst day, I am stuck in my house which can be very lonely. My feet have gotten worse over time. 15 years ago, I began getting blood vessels and nerves in my calluses. Now, I can't trim them without severe pain. The pain when walking has increased 3 fold or more since then. My symptoms seem better after I take some Ibuprofen. Staying off my feet helps to ease the pain. Cooler weather seems to help as well. I am worried that I won't be able to take care of myself financially as I get older. I also worry that I won't be able to find a partner who will be understanding about my condition. My condition has caused me to be depressed and sometimes angry. I try to keep a positive outlook on life. Living with PC is a constant challenge just hoping to be able to enjoy times with family and friends. PC is always there to hinder my activities.

Susan K16 Thickened callouses on feet, causing discomfort when walking or standing for long periods Difficulty accessing public transportation because not able to walk distances. (Not able to drive) Job requires being on his feet--difficulty standing for long periods. When feet are very wet, Sam isn't able to walk. The callouses have worsened as Sam has grown taller and heavier. Not really. Symptoms are less at beginning of the day. That it will grow worse over time and that Sam won't be able to find work that doesn't require being on his feet. depressed sometimes. Embarrassed by appearance

Suzanne K16 Pain Keeping active is hard. I'd like to do more with my son so that he gets used to an active life. I'd like to work, to cook, to shop without pain. On the best days, it means limiting your activities to try to keep the good days going. On the worst days, you do nothing that involves walking or standing. The condition appears much the same, the blisters have lessened but the pain seems to come quicker and last longer. Symptoms are worse in hot weather. To stay within cold, air conditioned environments considerably improves the pain. Whole body needs to be cold, not just the feet. The things I'll never experience. Mood is greatly affected by pain. Extreme pain leads to impatience, frustration, anger. Prolonged pain leads to low mood and feelings of inadequacy.

Suzanne K6a Not being able to stand, walk without pain and when my nails are infected and painful. Not being able to take long walks or play outside with my grandchildren upsets me very much. Best days I can do a little house work for about 45 minutes and on my worst days I don't do anything but sit with my feet up. Born in 1951 but did not wear short

sleeves till 1975 when I got pregnant and my arms improved a lot. My feet have gotten worst as I got older. Feet mostly stay the same or I have more pain if I develop a blister(s). Staying off my feet is the best solution. When I have a finger (or more than 1 at a time) with an infection this limits my doing anything that is too stressful on my finger(s) because the pain and inflammation it too great. Not being able to take care of my fingernails as I get older (toenails removed when I was 3 years old) and they get more painful as they grow and I will not be able to care for them. Not at all. Just would like to see a cure or a way to diminish the pain so that I could do more with my grandchildren before I get to old to do so.

Sylvia K16 When I am standing for long times my feet start hurting. When I walk for a little bit my feet hurt. Jump rope, basketball, running, walking, skipping, galloping. When I jump rope I don't want to jump and I want to put it away right because it hurts. It helps me do the stuff I want to do when my feet feel better on my best days. On my worst days I feel like I cannot do anything, like I cannot move. I have gotten more calluses and they are bigger, harder and hurt more. They come and go. If I put my feet in the water for a real long time it helps them hurt less. If I stand around, or run or do any activity on my feet they hurt worse. That I cannot walk anymore. Makes me sad and mad. When I was walking today I started to fall down because of how much my feet hurt.

Tania K6a Nail infections Thick nails Blisters Miss lots of school, miss social activities and sporting activities trained for due to recurrent infections which are extremely painful. Best days can be normal/ok but still social difficulties like hiding hands from others. Worst days in extreme pain, depressed and crying Feeding impossible as baby but no problems now so this has improved. Nail infections becoming less frequent. Feet getting worse and particularly affected by hot weather Hot weather makes feet worse Use surgical soaps daily to prevent infections Determination at gets older. My son doesn't even know that it could/will likely get worse and I can't bare to tell him. He talks of careers which I dont think he could do such as military. How do I tell him Avoids new groups/places. Always wears gloves to hide hands. Extremely distraught when feet bad or has infections as misses activities important to him and that he has worked hard for PC project have been our only lifeline and give us hope for the future. Please help to find a cure/treatment so that my son does not have to suffer anymore.

Tate K16 Calluses on my feet affect me the most. On days when the weather changes and on random bad days, even after taking ibuprofen, the painful calluses are difficult to deal with. I often come up with excuses for why I walk the way I do. I am also unable to participate in many athletic activities and I am embarrassed when I am invited to play games that require removing my socks and shoes. Not only am I uncomfortable with the idea of people seeing my feet, but I am also uncomfortable sitting on the sidelines being the only one not participating in that game. It also takes a steady hand to trim down the calluses with a razor blade and I am afraid that I will lose my steadiness with age, leading to cutting on my feet accidentally, further worsening my ability to walk. I love watching sports and I would love to be able to play highly competitive sports like football and basketball with my friends. I have not lost my appreciation for sports because of this condition. I actively follow professional sports and I am

able to cheer on students from the stands at high school sporting events. The condition has simply altered the ways that I get involved in what I like. On the best days, I can finish out the day and climb in bed without my feet throbbing. On the worst days I result to crawling across the hard wood floors in my house. I usually try to push myself to do whatever someone without PC can do, knowing that I will pay the price when I get home and can no longer put weight on my feet. This is probably not a great way to live, but I believe the condition will only get worse with age so I may as well do all that I can before the condition keeps me from doing normal day-to-day activities. I am still young, but I have seen my condition get worse and worse through my teen years. The symptoms remain the same, just more intense. Calluses now form on my fingers from writing with a pencil at school every day and from tying my shoelaces. It is a gradual change, but thinking back to when I was 10 there was very little I actually could not do. Running laps was one of those things but it is the only thing that comes to mind. At 14 I was able to play football with pain only occurring after the games. Now at 18 and looking at colleges, I take into account the distance between classes, transportation options, and other accommodations. The pain is constantly present but increases in intensity as steps are taken. I typically rely on ibuprofen on really bad days. What worries me the most about my condition is that at any given point in my life, my condition is the most severe it has ever been and the least severe it will ever be again. I have a good sense of humor because of my condition. I know that I can look goofy when I walk but I can turn it into a joke that nobody thinks anything of. Wet feet hurt even more than dry feet. For this reason I prefer colder temperatures because warm temperatures cause my feet to sweat. This makes going to the pool dreadful. Swimming is one of my favorite things to do in the summer but between exposing my bare feet and being nearly incapable of walking afterward, I really don't find pleasure in going to the pool, especially with my friends (none of my friends, even from kindergarten know about my condition).

Terry K6a Callousing/blistering of the feet Walking varied distances; Standing for long periods of time; Running and romping with my grandchildren; Dancing with my wife. On my best days I can have a few hours of "smart controlled" walking. On my worst days I walk only when necessary. When I was an adolescent, my nails were surgically removed. While there was still some nail growth, it was not as massive and thick, so the events of trauma to the nails were minimized. Traumatized nails almost always ended with infection and loss of the nail, a very painful process. Most of my improvement over time has been the result of "managing my PC", planning for "smart walking", e.g., not over doing it and paying attention to heat, walking surfaces, and where "I would park my automobile". PC is always there so "don't make it angry" ðŸ˜–! Worse: wearing the wrong shoes; over walking Better: "Smart walking"; wearing shoes with a firm flat surface for my feet to land on, thereby minimizing the shearing action that causes the blistering; wearing thick socks (hunters' socks); Using my antibiotic topicals often to prevent secondary infection before it matures....itching is a clue that infection is rearing its ugly head. I have learned to manage my PC fairly well. I worry more about my Daughter and Grandson who inherited PC from me. I worry that they will have to endure PC for 74 years like I have. As a young PC'er I was often depressed, sad, and embarrassed. As an adult who realized that PC was going to stay with me, I became hopeful, and encouraged as a result of my own success in managing this disease.....I'm no longer depressed.....still a bit

sad....but mostly encouraged. Our conference gave me a huge dose of encouragement! I hope and pray that research continues with serious support from the FDA. I believe the PC Organization will be the key to final resolution of this horrible disease, and when that happens, I will nominate Mary Schwartz for sainthood ðŸ™†. In fact she already deserves that title.

Tiffany K6b Calluses, pain, cysts on face/ body Work Pain everyday while walking is very discouraging. I can't always do the things I want to do. I don't want to rely on pin medication everyday but that's what it has come down to. I've gotten more blisters on my feet over time. My toenails have gotten thicker over time. I've gotten more cysts on my face and body.

Pain medication (ibuprofen) is about the only thing that helps. And trimming the calluses every week. Getting worse. Not being able to work in the job I want to do. All of the above. It's awful.

Timothy K16 Painful blisters because it affects the amount of stuff I can do. I cannot run or play much sports on my feet. I can't play as much with my friends because my feet start to hurt and I have to sit out. Sometimes I have to sit out P.E in school. I cannot do lots of sports on my feet like running, karate and tennis. I am still managing to play football but after it, I cannot walk because it is so painful. My Mum loves walking but I cannot go for long walks with her because it is to painful. On my birthday it was really hot and I played football outside with my friends but after a while of playing it hurt so much we had to stop. On the best days it hurts after activities but on the worst days I can't even do the activities. Overtime, my symptoms have got worse because I am on my feet a lot, I am a lot heavier and I do lots of activities. When I was little I could play on the monkey bars but now I can't because I get blisters on my hands. Some days my feet hurt more than other days. I see a chiropodist every three weeks who shaves the skin off my feet and that makes them feel better but then it grows back. When my feet got hot and sweaty it's worse. Not being able to play with my friends, missing out. Sometimes I get sad but I try to focus on nother things. Thank you for trying to find a cure.

Todd K16 Pain due to severity even when doing meanial things. Cracks and infection management towards above worsening. Cosmetics of condition and explaining it to others Walk even in grocery store, park,etc Dance Run, jump etc Play ball with my kids Worst days not able to participate at all. On best days still very limited. Callus has expanded to 90 of feet and 30 of hands Cold makes it slightly better for me and heat much worse Infection vulnerability aspect Depressed at times, cranky and irritable ðŸ™† Gum disease and premature tooth loss Sweating a lot due to hypertension and pain

Tom K16 Calluses on feet Blood vessels pushing through calluses and when catching them have sharp pain Walk around! Kick a football with my boys. Walk anywhere. Work in the garden. Swim due to increased pain when walking afterwards Always have huge effect on everything I do. Best days are because I spend almost no time on feet. Worst result in crawling then having difficulty sleeping with foot pain Gradually got worse. Amount of time on feet has got less and less. When a teenager I could run if carefully selected when during a day. Now couldn't consider running ever. Walking small distances now has to be carefully

considered. No. Getting worse lowering quality of life. Knowing my son has to go through the same. Getting older and feet worsening. Frustrates and I believe gives migraines from stress of having to so carefully manage my days. It's always nagging so affects mood.

It's a tough one as I look fine to others and calluses to most people are an annoyance but not painful do there is no realisation of how much walking hurts.

Tom K6b pain limit walking/standing limits jobtravel walk hike exercise stand on best days: suffer thru pain to do normal activities or to socialize worst days: extreme pain, non-socialization, isolation, depression, can't work pain has gotten worse over time. callouses and blisters seem to get larger and harder to manage. more prone to infection. heal time is prolonged symptoms are mostly always there, just sometimes pain level is only a 4 vs a 7 to 9 haven't found anything specific to make symptoms better on consistant basis my health, ability to exercise. depression, isolation, frustration, affects the ability to do things with my loved one it has a been long journey, and yet, when trying to get help or relief, 99.9% of Doctors think its something else, offer little or no help, and when asking for reasonable accommodation at work or anywhere for that matter it gets denied because they don't think anything is really wrong with me. social security is a fight and nobody reconizes this disease

Vicki K6a My PC effects me the most when I'm on my feet for long periods of time. The pain not only effects my feet but the rest of my body due to my gait. walking marathons I have a sit down job so my feet don't bother me much on most days. If I'm on my feet long, I will have pain and will get blisters at times. My condition and symptoms have not changed much over the years. If I know I am going to be on my feet for a long period of time, I will take Meloxicam prior and it seems to help. Being able to take care of my feet and hands when I get older. I worry about my daughter and two granddaughters who have PC too. I feel I have a high tolerance for pain having to deal with this condition on a daily basis. No thanks.

Victoria K6a Pain and ability to walk distances or stand for long. Affects my work and also social things. Yes my work as a sales wine merchant I struggle with the all day events as by midday the pain makes me want to cry and I become agitated and snappy . I would love to do a marathon or exercise more but just think of the pain and what more blisters will appear so decline Doing it Worst days it's deoressing and annoying more than anything as I want to do the things. Good day it's great at the start but any length of time on feet can change a good day to a bad day quite quickly Tongue has worsened . The books and cysts got better and nail infections less but blisters the same and pain the same Yes . Heat makes them worse . Cold makes them better . Wearing wide shoes and keeping off my feet a lot makes a massive difference and blisters can clear up but pain of burning is always there Passing it to a child - not her worries as I know it won't worsen or kill me Frustrating , annoying , can get me down at times and I think - why me. I would love to feel a normal step once in my life and how it feels to walk normally with no pain Would love to know more about teeth and if it has an effect on them decaying

Victoria K6b Pain with every step, depression due to weight gain, lack of sleep Yes. Standing, walking, dancing I wear rubber sandals year round, with toe socks when cold My feet have gotten wider. Walk Fit shoe inserts in tennis help my weight to be more evenly distributed, so less painful. Finding shoes that are wide enough not to cause pain, is a problem. Gaining weight. Depression, apathy, anxiety Please find a way to modify these genes, so others don't suffer

Youmna K16 Pain, because it is the most limiting symptom with the biggest impact on wellbeing and relations to others. All other symptoms are relatively less impacting So many activities as simple as walking without pain. Walking, standing, running, wearing nice shoes. I have organized my life in order to minimize the pain impact (eg. I go by bike to work to park as close as possible from the entrances and eat in my office to avoid going to the cafeteria etc.). However there are always elements that are not in my control (eg. meetings in offices that are far from mine =long corridors). On worst days I work from home if agreed with my supervisor, take strong pain killers and don't do more than the strict minimum and pain hit on my nerves. I don't think the symptoms changed over time, but I organized my life as much as possible to adapt to the pain symptom (handicap card, wheelchair in exhibitions, etc.). I can do a lot of things, but I need to do it my way which limits easy interactions with others There are periods of the year when pain is stronger, but I still don't exactly know why (weather pressure?) It seems that good and long nights helps feet recover better from walking effects. In mornings and evenings pain is higher than during the day. Not to have a normal life. Organizing my daily life costs a lot in terms of worries and energy. Each new situation and relation is challenging. I can be worried because of pain, feeling disconnected from other and lonely as I have to do things differently than other to adapt to my limits in terms of walking and standing, feeling embarrassed to have always the same type of non feminine shoes, feeling depressed and anxious when pain is strong and sometimes aggressive if relatives push on my walking limits. I have the strong sense that I am being very courageous to face this everyday life difficulty, which is valuable. And I manage to make other almost forget my difficulty. But I feel different from the people around me, and that is hard.

Valerie K16 the most boring symptoms are the pain that prevents me from living normally. the fact of not living normally leads to frustrations and moral suffering. there is no activity in particular, but it is simply sharing a walk with her spouse, toy with her children. shopping with her daughter the simple things in life. do not talk about sport! Having pc is the best days: - spend your time thinking about optimizing your travels. - leave your feet as far as possible in the air, without shoes, to limit the feet that swell and massage. - it's lying down and letting your feet rest in the worst days: - It's crushing your teeth - It's having the rage of this dirty disease - It's wanting to the whole earth - It's regrettable to live - Thank you heaven, I did not pass it on to my daughter it is a screwy circle: - with the pc we can not move too much to do sports (limit) -as we do not move too much we can gain weight - as we gain weight, we have even more pain in our feet - as we have pain in our feet we walk less and so on the symptoms are still there. What is certain is that heat aggravates the pain. In contrast, the cold is better, it's having to continue to work until you reach retirement age It's also difficult DÃ©pression Patience/tolÃ©rance for frustration

Ljiljana not known Bol. Setnja Ostanak u kuci celog dana zbog bola u stopalima Vise promena na kozi Da. Pogorsavaju se tokom letnjih meseci Sve

Kara not known Blisters and hard skin callous excessive pain , embarrassed for other to see bare feet. States "want to be normal " Thickness to all nails on both hands and feet require excessive filling to maintain usually every 4 weeks by my mum and a visit to podiatrist every 6-8 wks. This make nail beds very sensitive open to infected blisters if accidently knocked or stood on. Causing ectreene pain and discomfort. Very regular coldsores/ impetigo usually on corner of mouth or nasal passege requiring Constant visit to go to gp as the only treatment appearing to clear these up is fleuoxocollin (anti biotic) Swimming Football Running On the best days I try to feel confident about trying to explain my condition in the hope people won't ask again and again.-no bad blisters- no bad infections not having to do my nails!! The worst days , several infected nails ,blisters fill with rubbish so much I can't describe the immense heat and pain I constantly feel. A stranger asking me "what's up with us nsils"" with that horrible look on face. Children at school saying l"i have dirty nails, making fun of me and no one seeming to be busy They have got worse , more pain come with more blisters, increase in getting coldsores taking longer to clear out. Keeping feel dry n cool no heavy shoes that rub. Trying not to be clumsy and bashing nails etc If my children's will have the same condition. If people don't like me just cuz I have darker thick nails I do become very frustrated and done like change

Anonymous not known The pain, that makes me sweat at nervous while trying to perform "normal moving". My PC is as yellow as yellow could be, it is very obvious,present and so embaessing. I have to be carefull not to injure my fingernails, I have a favour for wearing gloves. Swimming eg is not funny in a pool, when I try to hide my feet. I prefair sandy beaches.. The sand sticks on my wet feet and covers my PC. I like doing yoga, but it is always a big discussion why I don't take of my socks I should make enduring exercises like jogging because I put much weight on. Best day: PC stil looking ugly but doesnt hurt Worst day. I have to take a very could feetbath to take away the pain Because I put some weight on it is bigger and at the heels it becomes like wood the nails at my hands specially the thumbs are really thick at my feet it is constant but at my hands it belong to what I do. Egg gardening makes worse I could manege much better if other people would be the same like me. In other words TO BE DIFFERENT when I have pain I can be very rude and not patientI always hoped that science would find a cure for my maybe children. Now I am 56. This issue is gone

Anonymous not known Foot pain walking Shopping, walking long distance, running impossible Best days, not a problem Worst days severely limit mobility Slightly better with age. Very painful when I was young Yes. Hot or warm weather make my feet hurt more Nothing, learned to live with it Limits my ability to do things I want to do My father acquired painful feet while in service in world war 2. He recently died at age 91, with callouses still on his feet