

Alejandro K16 Trimming calluses, use some creams to refresh my feet. prevented thickening of the callus so that it does not generate wounds when splitting because they tend to be very deep and painful. No change, It's the same, here the doctor's don't know how to treat the PC does not do anything for the pain, only in the thickness of the callus to avoid wounds and bad smell. does not have any impact. does not improve it at all. they have not worked The pain after trimm, I can't walk, even, I can't sleep, but I have to work AND I need ignore the pain something that reduces the callus without needing to cut it, that reduces the pain I hope can help US.

Alicia K16 Trim and shave callous every 2 weeks. Super glue cracks in callous. To help with pain. Soak in Epsom salt or bleach daily in shower. To help with itching. Daughter takes ibuprofen. Husband takes meloxicam, tramadol and gabapentin to help with pain. Trim and shave callous helps with managing the amount of calluses, pain, and so nerve endings don't continue to grow in them. Soaking in Epsom salt or bleach helps with itch and infection. Popping blisters helps them from getting bigger, pain and getting callous there. Over time you find different things work better. We've been doing that regimen for about 5 years though. It just manages it. It's just something they have to do to survive and get through the day. It doesn't stop it. It still hurts sometimes more but you have to do it or it'll be worse. Not at all. It just manages the callous. The prescription drugs help take some of the pain away. It's what has worked the best so far but it might change over time We have to carry around our medications, if we are going anywhere we have to make sure our feet are shaved in advance, it takes hours to shave our feet, it still doesn't take away the pain. Pain management. Awareness to doctors.

Alison K6a scrape excess skin on feet to reduce thickness and apply cream to soften skin. hard skin Have to do this more often as condition has got worse slows down growth of layers of hard skin Not very well Not very well They have become less effective Sore feet when skin very thin, pain as thick layers return, plus blisters Reduction in hard skin growth and pain relief

Amanda K16 Shave callouses, use retin-a cream, footfile, soaking, pain pills, super glue on cracks Thick callouses, huge cracks, pain walking, pain sitting, pain lying down More frequent shaving as I get older. It grows faster and effects more parts of my feet Not well. Hurts like hell after shaving down for several days. Followed by a day or two respite then repeat the cycle. Super glue relieves some accrue pain of cracks Not at all I can walk a bit better after super glue Less effective over time Very time consuming, difficult to contort myself to shave callouses. I care for a young child and sitting to let super glue dry is hard. Reduce the callouses. That would reduce the overall pain and the tendency to crack

Amanda K16 Go to a podiatrist. Use clippers. Thickness I yo lwss and less to the doctor. I mainly dont have the time to go or money to pay for the appointments and I use a scooter now so I guess its easier to ignore it. Not well. It doesnt do much for pain. The trimming of callus first makes my pain worse, then a little better than normal and then bad again. Not at all. It used to help a lot when I was younger. I used to go every six weeks. I've just gained

too much weight for it to make a difference I think. My doctor is just over 2 hours away. My insurance doesn't cover it. So I really don't go often. It's been 4 months now since I went last. Pain and the cysts. Those are super painful.

Amy K16 Unless too sore or inflamed, I try to do self-care on my feet weekly by using a callous scraper or single edge blade to trim the callouses and then file them flat; I use a pedicure grinder to file down my nails and then file them flat; I use special clipper to cut out the portions that grow curled into the skin; I gently file my fingernails flat and sometimes apply fake nails over them; I use a Dermalogica gentle exfoliator on my face to reduce the likelihood of acne; I brush my teeth, tongue, cheeks, and roof of my mouth daily and rinse with an alcohol free antiseptic wash and rinse with warm, salt water when sore; I apply a cream to the corners of my mouth and any dry patches on my skin before bed; I wash my underwear line with Yardley almond oatmeal bar and treat any cysts by lancing and draining them; if any areas appear infected, I begin washing the area daily with Hibiclens and applying an antibiotic cream and contact a physician if I am unable to control myself. Blisters/callouses on my feet, nails, mouth, and cysts/boils. Treatment takes longer because the thickening of my nails has worsened as well as mouth symptoms. Because of increased inflammation and lack of pain control, I am unable to complete my self-care treatment plan as often as I should. The first week after completing my self-care treatment plan, my feet are very sore. They are then better for about two weeks and then become sore again. I have to be careful not to cut them too thin or allow them to become too thick. They do not stop or slow the progression at all, only helps provide some pain relief. They help some for pain relief. They help some but are not as effective as when my condition was less severe. My self-care treatment plan takes a lot of time to complete and is very painful. Pain relief; something that would stop the cysts/boils or significantly reduce the likelihood of an outbreak and infection; something to make my nails not so thick or curl into the skin, something that would reduce the redness, swelling, and inflammation in my feet and hands. It would be helpful to allow access to opioid medications by specifying them as an approved treatment for PC pain. It would be nice to have a self-care kit with items needed to effectively manage the callouses, blisters, nails, and cysts that might include items such as a medical scalpel, file, grinder, etc.. The development of a memory foam type insole that provides good cushioning while being thin enough to fit into shoes without overcrowding the toes and feet would also be helpful. Maybe even one that provides Lidocaine or some other sort of pain relief?

Amy K16 Limit my walking/standing. Using a dremel tool on my feet at least once a week. Constantly researching and experimenting with different socks and shoes. Hot, burning and sore feet. I am more likely to spend money on experimenting with socks and shoes. Sanding my feet is the biggest help. I'm not satisfied at all with footwear. I don't know that anything slows it. I only wear tennis type shoes at all times. I don't think my calluses have gotten worse. I don't really have any treatments. Being able to walk painfree.

Andrew K16 Trimming and shaving every couple weeks prescription pain meds and every single day and strong narcotics when the pains really bad. I drive a truck so I can stay off my feet most of the day Pain is all I really care about More frequent trimming shaving of

the calluses it seems to help have more okay days. And religiously using my painkillers If 0 is nothing at all in 10 is completely perfect I would say I'm at a six or seven Not at all

Somewhere between good and okay Technically better now because I have gained great access to good medications I wish I didn't have to take narcotic painkillers because of the side effects and it's illegal to drive while taking them and they only work when I'm taking large amounts of them Elimination of pain

Angela K6b Trimming calluses Filing nails Trying to contain infections Wearing seamless socks Constantly looking for comfortable footwear Pain I need to trim and file more frequently Not well enough Nothing really helps They don't really help Not really changed Time consuming Anything that eases the pain of calluses

Anke K6b pedicure, insoles calluses, thickened nails first I did my own pedicure, now a qualified pedicure does it for me. And I got an other podiatrist that makes better (softer!!) insoles I am able to do what I want to do. Without insoles or pedicure I would have much more pain the pedicure makes some calluses even disappear, but other calluses only worsen, whatever I do very well, for example in doing sports very well i can not wear every type of shoe pain reduction, make the nails thinner, make the calluses go away

Anna K6a Ice, rest, special shoes and insoles, pain meds, cream, trimming and cutting Growth and pain Spend more time due to new calluses Barely Slight improvement It could be better It's time consuming Stop the pain I can deal with the ugly toe nails but the pain is the primary reason for treatment

Antonietta K6a Trim calluses, nails, wear custom made insoles, apply cream to skin Feet, nails, skin Same. Insoles are new as an adult and how I have them made for my daughter. Just makes it possible to walk without pain most of the time because if I didn't trim it would be very painful to walk They don't Reduce the pain some Time it takes. Must be done at least weekly. Also doesn't allow for me to stand/walk totally pain for and for extended periods. It's just better then if I didn't do it. Reduce or eliminate feet pain

Aubrie K16 My mommy trims, sands and puts cream on my feet. It does not treat the pain. It does not stop or slow the disease. Right after mommy works on my feet they feel better and I can play more. How long it takes and it hurts a little to have my feet worked on. I want them to feel better. When I walk to the breakfast table I go slowly because my feet hurt on the tile. I use flip flops in the shower because floor hurts mt feet.

Ayla K6c Keep my calluses shaved, but not too close where nerves or vessels are exposed. looks better, and increases my standing time a little. I try to spend more time the older I get. very little none very little very little Current treatment of shaving the calluses is time consuming and dangerous. I've cut myself multiple times. decreased pain when walking

Brad K16 Taping the cracks on my feet. Soaking every night before I shower. Trimming after I shower. Applying lotion/ointment. Wearing breathable socks and shoes. Taping keeps the cracks from worsening, and trimming keeps them from getting too thick. Airing them out keeps blisters from forming. Much more tape is required. Much more trimming is required. Soaking is required every day. Taping is effective at keeping cracks closed, but increases blistering and sweating. Not at all For short periods of time after taping I feel like I can function at 100%, but that quickly changes once blisters form. fairly well, but is a double edged sword because taking increases blistering. Expensive, time consuming, hard to explain if people see the tape. Clear up nails, reduce pain, thin and soften calluses.

Brandon K6a Covering nails during swimming Insoles in all shoes to soften walking Removing shoes where possible Pain medication on bad days Prevention of infections Pain in soles Foot heat Increased amount of foot cooling Amount of walking reduced over time Depends on the day Little effect Acceptable compromise when activity is important No changes in treatment effectiveness, since treatment is limited anyway Effectiveness is very limited Reduction of pain during walking Elimination of nail infections

Briannan K6a Cutting or trimming calluses on feet My calluses None... less walking. Better shoes It doesn't A weekNone Hasn't Time consuming Pain relief No

Buff K6a I use a dremel sander on my nails and callouses on my hands and feet. I use various creams and ointments to sooth and prevent cracks, itching and infection. Right now I am taking meloxicam daily and Tylenol PRN. Unsightly symptoms (thickened nails and callouses), pain, infection, cracking, itching. As a child and teen I soaked my nails and callouses and trimmed them with a razor blade. I prefer the smoother finish of sanding as an adult. I call it "sculpting" my feet and nails. I am able to manage enough to function on a daily basis but not without pain. I hesitate to increase the volume or type of pain medication I use due to other adverse effects on my body. They don't. I am able to function in my daily roles as part-time employee (30 hours/week) and mother but not without pain. As well as ever. I wouldn't say I've had any treatment failure over time. I worry about the adverse effects the pain medications have had or will have in my body. Other than that, they are just time-consuming (an comparison to someone without PC). I would be most grateful for something that addresses and corrects the source of the pain, as opposed to masking it. Stopping or reducing the blistering and callousing would be ideal. Correcting the appearance of the nails would be a nice bonus. I am more concerned about the pain than the cosmetic aspects. Not at this time.

Carl K16 Reduce and level foot callous as this seems to minimize paid during walking. Wear heavy soled shoes as this also seems to better distribute load and minimize pain Pain - also visual reduction. 1- mother trimmed callous 2- I trimmed callous 3- Podiatrist periodically trims callous and I make needed adjustments It reduce pain to a tolerable level for a moderate period of time Not at all effective They allow me to participate to a level.. Treatment works about as well today as it ever has. Potential for cuts and infection. Reduction of pain without addictive drugs being required.

Carmen K6a have a normal live. Only creams but nothing really improves pain. Pain when walking. I have gone through different treatments such as anti mitotic creams or pills, retinol A, etc and I think now, with my 71 years old and do not expect to have a cure before I die. It is the best I can do. For me resting is the best treatment Attending three times a week to a gym for functional exercises with no stress on my feet. My work is basically sitting on a desk and I have to walk constantly a few steps to continue. I do not dance anymore I love traveling and I must think a lot where to go to decrease need to walk. The last best was a safari in Kenia where I couldn't get out of the vehiche because of the animals. I try to choose places where I can find wheelchairs cream to reduce pain and blisters Walk in a cloud Flying instead of walking. My everlasting dream

Carol K6a It has been very helpful that so many podiatrist are aware of this condition. So now I am helped by them, instead of insisting I have a sample sent to a lab that do nothing about PC. Very thick toenails. When younger my nails were not as thick and I had less callouses. I could do the care myself. Very good. It doesn't. It is easier to walk. My nails no longer get infected. This could be, because as an adult I don't bite my nails or play in the dirt. The only treatment is having my nails cut by the podiatrist. Only the nails can't ever change. I strongly when younger hated nails commercials. Comfort. If a nail becomes infected soak that nail an at the correct time use a sterile needle to enable you to release the pus.

Catana K16 Taking pain medications and taking care of feet and my nails.
Everything. Its gotten worse as I have grown older. It is more painful. Not very well.
Not at all. Barely. Barely. I spend more time and there is no improvement. Shrink my callouses.

Timothy K6a Taking a Simvastatin drug to reduce the effects of the mutation.
Calluses and blistering Not in the last 10 years. Partial improvement.
Blistering and calluses are not as bad. Pain and mobility is still an issue every day. see comment in 29 Partially, limited. As I age the condition does become worse, despite the treatment none Treatment that deals with the calluses and blistering, which is the most debilitating part of the condition.

charles K6a Trimming. Limiting walking Pain and blistering. Not in the last decade. Fairly well. Not at all. Fairly well. Fairly well. Still blister. Stop blistering.

Christine K6a trimming callouses, popping blisters on the feet, argan oil or lotion on feet at night, file down fingernails and toenails. callouses and thick nails More frequent trimming of callouses is necessary as she gets older and more active. Tries to keep the callouses under control to avoid increased pressure and foot pain. This does not slow the progression but it manages the current symptoms. It helps to manage the symptoms so

the pain doesn't increase. It is temporary management and doesn't help the disease in the long run. Decreased foot pain with standing and walking.

Claudia K6a Applying ointments, daily care of nails, limiting time spent on feet. Nail infections, try to reduce pain and blistering on feet Takes more time now. There are more symptoms so we have to try more solutions. Badly. I'm not convinced that anything we're doing actually works. They don't. I'm not sure that there is a difference... except for limiting time spent on feet. It's about the same over time Time dedicated to care when not really sure if it works Control of pain Control of blistering More normal appearance/shape of nails (also important from a functional point of view) No thank you.

Danielle K16 Shaving, sanding, applying lotion, taking Advil, resting often/ not much activity, being cautious with activity. Pain from the callouses being to large or uneven, keeping the callouses down, trying to stop them from spreading to much. Some callouses will grow under my toes and cause splits under the toes, so I must watch to prevent those, otherwise I'll have to deal with open sores under and between my toes. Unevenness from callouses makes walking uncomfortable and painful, so it must be level. Less shaving, as it makes the callouses worse I believe. The constant shaving makes the callouses possibly grow bigger and thicker. They help keep the callouses moderate. I try not to let them grow huge or uneven. Advil helps manage the pain for me, and constant watching helps prevent toe splits and cracks. The Advil helps with pain, constant watching and occasional shaving helps keep the callouses from becoming to large or from growing under/ between my toes, clipping nails to prevent over growth. Depends really? Advil helps with pain, so I can do daily stuff easier because of that, but grooming wise always depends. Some days its good, others, not. Since my condition has spread and seem to be on a path to overtake my foot, my treatments work a little. They help me manage enough to get through the day when I need them. I take Advil when I want the pain to stop, and shave or sand when the callouses get to thick and walking is uncomfortable or when they start cracking. Shaving makes the callouses worse and risk me getting cut by the razors (I have been cut before). Shaving the callouses off leaves me very tender footed and slow, as the "skin" underneath the callouses are tender. Little to no pain in my feet so I can be more activity and possibly do parkour. When we use to have a trampoline I could only jump on it with shoes on. I can't go in bounce houses, on water slides, or other fun activity with out facing the risk that i will be in pain because it just hurts my feet. And that hurts me.

Darlene K6b soak feet for 15 minutes and use callus shaver and file calluses and toenails apply vaseline or lotion thinning calluses decreases pain but still have burning no same as above shave calluses every 2 weeks by thinning the calluses pain can is slightly lessened they don't they don't same have to maintain shaving calluses and filing toenails relieve pain and burning of calluses and blisters beneath calus slow down the formation of callusing and thickening of toenails

David K6a Keeping calluses trimmed and nails maintained. As well as lotion my hands and feet to prevent dry patches. Take ibuprofen Pain It's reduced my pain so that I can work 9-

12hrs a day with a little help of over the counter medication. Makes life manageable. Able to be productive and active on a regular basis. It's and everyday process. You have to stay on top of it. It allows me to push myself further and try new things. Longer activities on my feet.

I never use to be as adamant about this growing up. Now that I've gotten a little older it's apparent I need to address it more instead of just dealing with it. Takes time and money. I would like to walk like a normal person instead of staring at the ground constantly so I don't step in the wrong spot and feel pain. Stay on top of your calluses and spend the money on shoes and socks. Manage your pain to your ability.

Denise K16 I try to keep my callouses trimmed, it helps decrease the pain. I put lotion daily on my feet to help keep the callous soft and to try to avoid cracking. Pain, more pain if the callouses crack. Not really. I have just gotten better at understanding what helps with my PC. It keep the pain manageable. They do NOT stop or slow the disease. I am able to keep the pain within tolerable limits so I can work, and do things in my daily living that are required. They have stayed the same. They are needed constantly. I hope as I age that I will be able to shave my feet by myself to maintain the callouses. Decrease the amount of callous growth which could then decrease the pain. Find pain treatments that are tolerated better by the other organs in my body. I have chronic kidney disease due to taking naproxen for so long. I really find encouragement by hearing from other PC patients and their families. WE ARE NOT ALONE!!!

Denise K16 Soak and trim calluses and nails as needed. Apply cream as needed. Take Gabapentin daily. Take paroxotene daily for depression. Use cane, rollater or scooter. Elevate feet when possible. Pain from calluses and nails on feet. It's just become more difficult to be able to reach calluses and nails as I get older. Don't like doctors to trim because they go too far and it becomes more painful. Not very, but without it I would become a recluse. They don't. Somewhat, but the pain never goes away. Just help me get by but it's getting harder. Always need to have single-edge razor blades and large nail clippers if I go away for a few days. Can never know just how much pain I'll have each day. So unpredictable. Can never really plan. Less pain. It's just so hard to explain the condition to people. The unpredictability makes planning activities difficult.

DHARA K6a Apenas evitando aquilo que eu sei que poderãj piorar os sintomas. Nãoo faãso nenhum tratamento hoje em dia. Nãoo funcionaram, a ãnica coisa que mudou foi a aspereza da pele. Algo relacionado a diminuir a dor.

Diane K6c Using razor to shave calluses and needle to pop blisters. I also take IBProfin as needed. Pain, discomfort No Helps to minimize the pain but does not eliminate the pain Shaving off the calluses and popping the blisters with a needle slows the progression. They help alot, However, the pain is not totally eliminated. The treatments work the same as they always have. No difference. I am not as flexible as I used to be so it is more difficult to shave down my calluses. Help reduce or eliminate the pain so that I can remain active for longer periods of time on my feet.

Diane K16 I wear custom insoles, special shoes, take prescription medication, stay off my feet, don't do a lot of the activities I would like to do all because of the pain in my feet from PC. The things I do for my feet to help with my pain, it does a little but not really. I've had to take more prescription medications, get custom insoles and shoes. It's always because of the pain and the hope that I can do more on my feet. Not too much. On a scale of 1 to 10, 10 being highest, I give myself an 8. It doesn't stop it. A little bit. Not much. They just don't do a whole lot. I really don't like taking so many prescription meds. But I guess I'd rather walk than not. To lessen the PAIN! I dream about being able to walk Barefoot in the grass.

Diane not known Taking 250 mg Fluconazole a week. Using a barrel sander on the end of a Dremmel tool to sand away the thickening on nails and bottom of feet. Apply Amlactin lotion to bottom of feet 2-3 times a day. Applying Vaseline to bottom of feet 2-3 times a day.

Thickening and cracking of skin on bottom of feet and nails. I use to use a single edged razor blade to shave down the calluses on my feet. Now I use a Dremmel tool to sand them. It cuts down on the soreness and infections since I'm not cutting myself anymore. It manages the symptoms quite well. The sander allows me to shave the calluses down farther without cutting myself. Therefore, I don't have to shave my feet as often. I use to shave them with a single edged razor blade every other day. I now use the Dremmel once a week. I can walk much better and for longer periods of time than I did before. Very well. The time it takes from my daily activity. I would love something that would make my nails look nice! I can live with everything else. No. Thanks for all your help and caring.

Diane K6b I trim my callus with razor once per week sometimes twice. I take Apple Cider Vinegar (4tbl) daily, I take 4,000 mg of Turmeric Curcumin daily, I wear shoes only outside the house, inside its slippers. I soak my feet in Epsom salt and apple cider vinegar as needed.

calluses on the feet my calluses seem to be thinner and I do not need to trim them as often. Makes it easier to get through the day. It does seem to slow the growth of the calluses. I still have the pain so the treatment does not address the pain, I still need to limit walking and running is not an option. well, if I do not use them my calluses get worse, I went off the ACV and Turmeric for 2 weeks and noticed a significant change in my calluses.

The time it takes to trim the calluses, then the pain for the next day because I trimmed them. I have to do it myself since I have not found a podiatrist that understands the blood vessel issue within the calluses. How can I lessen the pain when walking so that I do not have to worry about the amount of time I would be on my feet before doing activities.

Djoeke K17 Pedicure and cream and pain medication and insoles All over my body: skin, hands, nails, feet... More frequent to pedicure Helps a bit They don't Walk on insoles helps Good insoles work so i can walk With every 4 weeks pedicure visit Pain is there, but barebel Pain reducing, blocking gen mutation that causes PC Hope there will be a cure in time for my daughter 3 years she has PC as well.

Elie K16 Trim/cut off calluses pain only my pain treatment that has increased with age decrease a very little the pain none of my treatment stop or slow my disease no taking more tabs against pain no downside, I am already at the bottom of the hole remove or reduce well calluses on the sole of feet and reduce very well pain, so I could sleep every night and maybe walk a little my feet are less painful and less calluses when I do a detox diet and sport at home for some weeks. I am able to walk a little after.

Elina K16 Trimming, cutting off callouses. Pain, discomfort due to malformed foot sole from the hard callouses, appearance, ability to wear certain shoes It has not. It's less painful when callouses are smaller. Though that doesn't last long. Not well. They help. It's what I do. It helps. The day of or after I trim them the feet are raw and painful so I have to make sure I do the trimming on the days when I know I won't have to be on my feet all day the following day (work or family trip, etc) Softening of callouses? Numbing of the pain

Elise K16 Cut of calluses on feet and on hands and trim nails on feet and hands once a week after soaking in bath. Every morning and evening smear feet and hands with cream (Scrundena from Laufwunder). Special neadless Bamboo socks. wearing skechers with memoryfoam. at home mostly soft slippers. sometimes pop blisters when they are swelling it makes it more bearable I followed a training as a pedicure to do my sons feet and hands. Ian, my son, tells me what he likes most. It only makes it bearable. the pain stays, but when the calluses won't be cut, the pain gets worse. Also the cream and soft shoes and socks make it more bearable. It doesn't stop or slows it. Ian can walk little bits (less than 50/100 meter) but when I don't cut the callusses he cannot walk at all these treatments aren't changed sometimes its hard to do Ian's feet because he has extremely much pain and sometimes he doesn't have much pain on doing his feet and hand once a week, mostly sunday, we have to cut callusses and trim nails. We usually are working on it for three hours. First in bath and then cutting and trimming. So every week our weekend is about doing feet. Getting rid of the pain on feet and hand so Ian can walk and do the normal things without being limited.

Eliza K6a take simvastatin and sorriatine daily, use effexor cream on the nerve callus, use argan oil to remove callus, pain medication, have wheel chair and crutches, and crawl around. pain and nerve calus Prescriptions seem to become oneffective over time, especially on the nerve calus helps cap the pain to a more tollerable level and helps me recover quicker from bad days Works moderatley well, I think I am more functional I can recover quicker and cap the amount of pain or severity of the pain I experience They seem to loose effectovness over time, either my body is gettong used to the meds and they arent as effective, or my condition is worsening Bad sode efects and I still experience all the same syptoms, just sloghtly less severely Lessened pain, ability to walk and stand for longer periods of time with less pain and tissue damage

Elizabeth K16 I trim/grind my calluses and nails. I try to do it twice a month but it takes a lot of time to do it right, so in reality it's usually once a month. Calluses on my feet and thick

nails on hands and feet. I'm still relatively young, I haven't really changed what I do much, but when I was a kid my mom took care of my nails and calluses and she did it very different from what I do. She was so afraid of hurting me. I'm really unsure if my treatment regimen has changed at all. It doesn't really help with the foot pain, it just stops the pain from getting worse, it never really makes my foot pain any less than normal. It does pretty well because I am trimming them before they can get progressively worse, although new calluses can still grow. The really don't. It's worked pretty well but it has its limitations. They take so long to do, I'd love to trim/grind them a lot more often. Foot pain relief that doesn't come from addictive (or potentially damaging to my body) pain pills. Thank you so much for doing this!

Emma K16 I trim my calluses at least 4 times a week. I wear cushioned socks, insoles, and tennis shoes. I put "Healtastick" on my feet every morning and night. Pain!!! I've had to increase how often I trim my calluses, but the pain has still increased over the years. It lets my walk or stand a little longer than if I do nothing to maintain the calluses. My treatments have not stopped or slowed the progression of my disease. It lets me do slightly more than if I didn't do anything. The pain and calluses have continued to increase despite my attempts to reduce them. They don't control the pain. It takes a significant amount of time. Tennis shoes aren't appropriate for many situations. Reducing the pain!!!!Thank you!!!!

Erin K6b I regularly trim and sand the calluses on my feet. I also cut and sand the thickened nails on my feet. I take pain medication in advance, especially when I know that I am going to have to stand or walk. I will often crawl at home, which gives my feet a rest. I also use a cane part of the time. They address the calluses on my feet, and the pain. I have had to focus more on my nails, because they have become thicker and more painful over time. Also, I have more calluses and fewer blisters, so I don't have to care for blisters as much, and instead spend more time maintaining the calluses. It helps a little. Trimming the calluses seems to help relieve some pressure and pain. Painkillers sometimes help to relieve the pain, but sometimes do not even touch it. Using a cane does enable me to walk farther than without it, and it helps with balance issues caused by foot pain. They don't. It continues to worsen, regardless. They do help. Trimming the calluses makes sandals/shoes a little more comfortable. The cane and painkillers enable me to walk farther. I would look for something that would relieve the pain.

Erin K6a Trimming, filing, and sanding down calluses and nails; epsom salt soaks as often as able; therapeutic rest; lancing cysts; creams as needed for calluses thickened nails, calluses. It hasn't changed much, but I do need to spend more time working on problem areas than I used to. Ingrown toenails have become a constant problem lately. It keeps things at a basic maintenance level, but does not really improve things. Not well at all. The calluses regrow within a matter of days. Somewhat, but there is not much improvement. About the same. Maintenance level, but no real improvement in symptoms. They take a lot of time. Improvement to pain levels, decreased incidence of cysts, corns, and ingrown toenails

Esther K17 Use Dremel on nails Lance cysts Wear socks to slow blisters Painful cysts
Thick toenails Blisters I used to go to the Dermatologist a lot, now I lance cysts myself if I can reach them. They still get infected sometimes and no matter how many I remove, they come back. I think age slowed the progression. I have become better at hiding my skin and feet. I don't swim or sun bathe or wear low cut tops. I don't have to remove as many cysts now. I can't reach my back or the back of my neck. I would love to not be ashamed of my body. No

EVA K16 Trim and creams, not getting involve in any activity I know can provoke me pain
The hardness and thickness of the calluses I've never been treated so far, I'm with the first treatment Not so well, it doesn't manage to reduce the thickness and consequently the pain They can't slow down or stop it They actually don't improve it For the treatment I have to sleep with socks, wich provoke me some discomfort 'cause the heat a treatment that ends the pain

Fabiane K6a Trim, cut, file nails. File Calluses and put cream . Exfoliation and hydration for arms and legs due to Follicular hyperkeratosis. thicker nails, calluses and Follicular hyperkeratosis When i was younger I used to care for my feet every two weeks. Now I feel i need to give it more attention in shorter period of time guess i do the most I can to keep avoid thickness to be grosser than what it is if i dont care it gets worse, so I think it does slow the progression Cannot use normal woman working shoes if i do not care for PC, or walk long distances without having pain worked the same way since always. no improvement, just keeping it to get worse I have no time. My life is very busy and i have to care for my nails and sons nails very constantly and it takes time because child does not like trimming nails some medication that could reduce thickness of nails

Fran K16 I apply an ointment at night. I apply a foot cream in the morning. I use waterproof adhesive take to cover cracks which help me walk. I take antibiotics when needed cracks....puss as I get old I get more cracks....much deeper cracks.. cracks taping a crack means I can walk. The moisture retained in that area means the callous gets saturated and I can easily peel off the dead skin. I do Zumba.....I take meds before hand.....I check cracks and tape them up....I go home in pain.....but its okay because I have those exercise endorphins getting me through it all its the only thing that works and allows me to have a life If i run out of tape ---- i dont walk. If i develop a crack at work I am at a loss if I dont have tape with me.. eliminate the pain.....I listen to people tell their kids to stay off their feet to save them...but the callous gets used to that....I make sure I use my feet every day to some degree....that has helped me to keep going....If I get sick and stay off my feet for a few days its the worse because then my feet fight back even more when I walk on them....

Frank not known Trim often to keep growth from getting too thick. Would like to figure out a way to get nerve endings to recede, or subside when particularly troublesome. Trim often to avoid cracks that may promote more nerve and vascular events. Just learn to not wait until it hurts to bad to try to walk. Trim often, even when you know it's going to bleed and hurt. My concern is, being diabetic, at some point these bleeds may not heal well. Not well. They

don't. The only thing that can help is to stay off your feet. Whatever you do to make it so that you can spend more time on your feet only comes back to you in the form of the more callous growth. Not good, but best I can do. When trimming callouses I sometimes cut myself unintentionally. Twice it was badly. Cuts in calloused areas don't mend well. Something to slow the growth. Just that it would be nice to have a website or contact list for people you can get in touch with for descendants that might want to investigate opportunities to avoid passing on the gene.

Gail K16 applying creams where needed and taking medication N/a N/A N/A
it does not it does not not at all N/A make it look better and be free of
pain no

Gary K16 Nothing really - just daily cream Not changed none none none
none none

George K16 there is nothing you can really do. take pain killers to get through a day
cut lumps of feet I put a lot of petroleum jelly onto feet which softens them, but makes them
even more itchy. then you scratch them and it makes them even more painful, there is no
winning just softens the skin, which is normally extremely hard, so it is easier to cut or
scrape off not really It doesn't. it manages it so I can work it doesn't they
don't pretty much the same over the years its just a management/balance thing. you
try not to do anything that is going to make it worse pain relief itch relief I know I will
never really walk now because I have had so long with such limited walking I have almost
forgotten how to do it without the PC gait. I would love to walk even around a store without
pain concern over any side effects or causing other long term problems

Graham K16 Use razor blades for trimming feet and hands. File nails. Apply Melrose
ointment. Take pain killers. Hyperkeratosis and thickened nails I take various amounts of
Accutretin. It's useless It doesn't Occasionally I can walk a bit further and
occasionally reduces pain. But the side affects become unbearable. They've had no
lasting improvement Split lips, more blistering and tiredness That's a very disturbing,
depressing and disappointing question

Gwen K16 Trim calluses almost daily with a scalpel and ped egg Take a minimum of 2
Excedrin daily, sometimes 4 Pain Trim calluses and toenails far more frequently I am
able to function with limitations. Can't walk on uneven surfaces or for extended periods of time
or distance. They do nothing to stop or slow the progression. They allow me to walk with
little or even no pain as long as I stay within comfort boundaries (walk with thick socks and
sneakers on smooth surfaces). I have not had to utilize mobility devices yet. Worry
about use of Excedrin for decades and the effects it may have on my organs Eliminate pain
without dangerous side effects Just grateful for research that is being done on behalf of
PCers. Pray that the gene can be isolated and eliminated so future generations will be free of
"the curse".

Heather K16 Soaking and shaving off calluses weekly. Followed by pumice.
Urea/salicylic acid Keepin the calluses smaller Poor to fair Not at all
Sometimes it makes it better but other times it is much more painful No change
Time intensive, costly at times, painful Decrease pain and appearance

Helaine K6c listerine soaks twice a day wool socks all the time stay off my feet whenever possible bike not walk trim callouses every week take ibuprofen every day for pain relief pain callous growth not much, but it has taken the edge off takes the edge off the pain, but the pain still comes when I'm on my feet. Esp in warm, humid weather. I can take about an hour on my feet a day, maybe 2. That's it. They give me an extra hour or two of reduced pain They help me get through a significant portion of my daily activities with less pain. pretty well Takes time. I have to be extra efficient--I soak my feet while brushing my teeth or reading. pain relief I am very grateful to the PC Project.

Holly K6a I take Dilantin (to help the occurrence of blistering sores to appear less), I take Celebrex (Rx) for pain, and I take Tylenol throughout the day for breakthrough pain, but none of these medications totally take away the pain. Now that I'm retired, I limit my walking (and wearing of shoes) as much as I can. When my feet are throbbing with pain, I soak them in ice water to tempo OTC pain killers & ice water soaks attempt to treat (I.e. lessen pain) for the painful blisters, bleeding calluses & itching of the sores. My treatment regime has been consistent over my lifetime with PC, except for the addition of Dilantin in 1980 (which I continue to take). Treatment regime is poor; NOTHING stops the pain/blistering/itching/bleeding. The only thing that has ever slowed the incidence of blisters on my feet is use of Dilantin. I still get painful blisters, but they don't occur as frequently. (I know of no other PC patients who take Dilantin for this reason, but it has worked some in me.) I would like to see the FDA keep this in mind, as there may be something in this type of drug that may help others. None of my current therapies improve my ability to function normally. I take OTC meds for possible pain relief, hoping that they'll help, but they don't. When I was younger (teens through my 30's), I used to take 18-20 Excedrin per day for pain relief; however, I ended up in the hospital twice with severe gastritis due to taking so many aspirin. I changed pain relievers (which helped my stomach) but NOTHING alleviates the constant pain. You learn (because you have no choice) to live with the pain, but it's a very stressful lifestyle. Downsides to current treatment - I have found no OTC pain relief that helps with my PC pain (thus limiting my walking, standing & participating in most activities). Upsides to current treatment - None (except for use of Dilantin, which I've taken now for 38 years; I can't prove that it still works but I'm afraid to stop taking this medication). An adequate pain reliever would be optimal. In lieu of that, any kind of an effective numbing agent (for the feet) would be helpful & welcomed. To the FDA - thank you for listening to us (the PC patients) about our rare, debilitating condition & needs. Please help us.

Ira K16 I take a 25mg acetretin pill daily for the last 20 years which seems to help. Trim feet approx once per month. Soak when necessary and take pain medication. pain it has not changed in 20 years simply trying to manage the pain Does not stop nor slow the

process minimally minimally Having to trim once per month, which results in
tenderness perhaps an ointment which could lessen pain

Jack K16 PC pain feels like someone is sticking pins and needles in the bottom of my feet. It's a deep ache that cuts all the way to the bone. 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. Pain No change, although I try anything and everything new (no matter how weird). Not at all well! The plan is constant, consistent, and ever-present.

Not at all well! Barely gets me to the table to participate. Not at all well! Time and attention it takes away from personal time with family and friends. Reduce or eliminate pain. I wrote a letter to my PC that answers this question fully. Here it is: Dear PC, Well, already a bad start. You're not so dear. So let me start again. Hello PC. Yeah, that feels better. Hello PC. When I first met you, I was six months old. I didn't know who or what you were. But then again, I was six months old! But more importantly, neither did my parents, family, or my pediatrician. Looking back, it makes sense that no one knew, as I've since learned that I'm a spontaneous case, meaning that my PC is spontaneous and not inherited. Lucky me. But also, lucky you. Because you get to know me. When I was three, Dr. Sidney Barsky figured out the mystery of who and what you were. I was a bit lucky to find out so early in life even though Dr. Sidney titled the report Pachyonychia Congenita, (???) After all, it was 1965. The report was very clinical and I quote "A three-year-old boy is presented, who since birth has demonstrated nail and skin changes of the thumbs, index finger and mid-fingers. Since 6 months of age there have been similar changes noted on the first, third and fifth toes. The condition has become progressively worse with new wart-like lesions developing on the skin of the hands and feet. No other members of the family have had a similar condition". Close quote. And the rest is history. You made your grand entrance PC, and what an entrance it was you narcissistic pain in the hands and feet. My parents read the report and kept reading and reading, certain they would get to the section labeled cure. Which of course never came. Ok, no cure, but how about treatment? There had to be a section on treatment. Again, no luck. My parents weren't devastated because they had no idea what this condition meant for me, or my life. I call it blissful ignorance. In the 60's there was no Internet, no Mary Schwartz, and no PC Project. Well there was Mary Schwartz but we didn't know her then. And there was no one we knew who had the condition. So my parents and I learned how to deal with you. What other choice did we have? We survived your terrible infections! Boy they hurt. Were you angry with me during those episodes? We survived the monthly foot doctor appointments where my doctor used a scalpel to hack you off. Boy those hurt too. But we survived. And we learned to live with you. Because you weren't going anywhere. You moved in and you were settled. Curse you PC! I hate to admit it PC, but you've changed my life and I hate you for it. I hate you for making my finger nails ugly, so ugly that other kids made fun of me growing up. I hate you for making me walk "weird", now affectionately called the "PC Walk". But back then the kids didn't see any humor or compassion in my walk. I was just different and that made me a target. I hate you for preventing me from playing most sports and for dreading PE class. I hate you for the pain you cause. The pins and needles feeling, the deep ache that cuts all the

way to the bone. I hate that even when I treat you well, even baby youâ€¦ hot water soaks, cold-water soaks, elevating my feet, rubbing creams on you, massage, Vaseline baths, whateverâ€¦.you're never satisfied! You still cause pain. And I hate that the pain you cause makes me grouchy and lash out to the people I love, work with, and even total strangers. Sure PC, you can wave your victory flag, because now you have an organization built around your name and it's all about you. And you can add me to your list of the thousands of others that you have managed to infect like an unwanted houseguest. Oh PC, just your name drives fear and misery into the hearts of parents and prospective parents everywhere. Like a selfish partner, you stick, you hover, you cause pain, and just when I feel I may have you under control, you swoop in via an infection or swollen feet. Wow, you must be quite proud of yourself, for the power you have over my life and me. So PC, I want you gone. I told you before you changed my life. And in your infinite arrogance, you assumed it was for the worse. HA! Guess what, you were wrong. While I certainly don't love you or even like you for that matter, I do respect your power. You've made me a stronger person. You've taught me how to be courageous by exposing you to legions of doctors interested in learning more about you and by standing up to bullies who have no interest in learning anything about you except to use you as way to call me out as different. You've taught me to persevere by never shying away from giving my son a long, walk-filled day at Lego Land and Disney World. Or by walking 10 blocks with clients, who say, oh let's walk to the restaurant, its just a few blocks from here. Or walking the cobblestone streets of Venice and Rome with my husband. You've taught me understanding. Understanding for others who are different from me, politically, socially, educationally, and economically. It's a skill that's helped me build a successful business and for that I'm grateful. You've shown me how to understand myself by teaching me how to take the time to listen to my own body. Listening to when my body says enough alreadyâ€¦sit down, get off your feetâ€¦relax. You've shown me love. Love of a Grandfather who decided he can, and would, single-handedly cure you. One of his most ambitious and innovative tries was cutting and slicing lemons off his lemon tree and taping them to the bottom of my feet for an hour, followed by wiggling my feet on a sandy Florida beach until the callous just scuffed off forever. Love of friends, who through to this day offer me a ride on their back, literally. And love of strangers, who offer a seat or a look of "I get it", or "Whatever it is, I hope it gets better." You've given me "feet night" at my house, where once a week I get to have important conversations with my son as he helps me prepare my footbath and feet shaving. You've given me some of the most vivid dreams of being a runner in the Olympics, winning Gold, and standing on that platform, pain-free, for hours. You've taught me how to out crawl anyone else I know. Not an Olympic sport yet, but one can hope. You've shown me how to be comfortable in the face of randomness. Yesterday my feet were fine. Today I ache. What changed? Nothing. It's just you being you PC. But now I'm less of a control freak and understand that sometimes life just happens without an explanation. And that's ok. You've taught me the power and fine art of collaboration, or the act of working together with someone else toward a common goal. Collaboration between doctor and patient, boss and employee, board chair and board member, spouse and spouse, father and son, the list is endless. Through the PC Project, the organization devoted to your demise, I learned definitively that I have you. No question mark here! You've been outed PC. And I quote, a heterozygous change of T through A was identified in exon 1 of the KRT16 gene, resulting in the replacement of

Leucine (CTG) with a mutant Glutamine (CAG) at position 128 of the resultant protein. This mutation is denoted L128Q of Leu128Gin. How'd I do Frances Smith? You thought you could hide, PC? No way Jose. We know you. Also through the PC Project, I've met my heroesâ€¦ People like Mary Schwartz, Jan Schwartz, Roger Casper, Estovan Embarka, Roseann McGrath, Stephen Jiang, David Fowler, Robert Lindfors, Holly Evans and many others. The Project gave me the opportunity to meet for the very first time, other people who share this PC journey with me, giving me an education in who and what you are and why you cause pain, and giving me tips on how to partner with you more comfortably. So I'm grateful for the learning PC. But let me clear. I pray for the day you'll pack your bags and leave me the heck alone. I pray for the day that Roger and his team at Transderm obliterate you, or even minimize you. You deserve it and the Transderm team is exactly the right folks to make it happen. So my dear PC, my powerful painful partner, I thank you for the last 53 years together. And whether we have another 53 years, or are separated one day, I don't wish you ill, I just wish you gone, long gone. From, Jack

Jacqueline not known Pedicure Schoes All by myself Keep it in controle to have less pain Less None None New feet

Jacqui K6b I see a podiatrist every 3 weeks to reduce the calluses and corns. I treat my own feet every day with hydrating cream and wear insoles in my shoes The soles of my feet are very painful with 20 or more blisters or corns. These need to be managed daily. I used to pare down my calluses with a razor blade but do not have the flexibility to manage this anymore. Now I need to visit a podiatrist Rehydrating my feet has limited success. Having professional help (podiatrist) is what makes the most difference Nothing stops the progression of the disease, unless complete non weight bearing counts Paring the hard skin from my soles and removing the corns is a constant need For the first few days after treatment I can walk without much pain. By the end of the week however I am back to being very choosy with shoes and careful to limit distance Treatments have gone from seeing a podiatrist every 8 weeks down to every 3 weeks, and still needing a double appointment I am struggling with the cost of the treatment, and finding it more difficult to apply the creams as I get less flexible I'd like to see better education in managing the condition, such as wearing double socks, changing them twice a day and the need to apply cream twice daily.

James K17 soaking feet, sleeping with hands in gloves covered in a ointment. I also cover cysts with large Band-Aids and antibiotic ointments callouses on feet and hands being less active in older age I don't have to trim feet as often its still a burden and lots of time consuming. its just a temporary relief it doesn't stop the disease !! if I don't soak and trim foot callouses after time I wouldn't be able to put on a shoe and do any activity's again the treatments are needed to maintain a lesser amount of pain, The pain is always there so I guess I'm saying they don't work LESS PAIN PLEASE

James No Forms I see my foot doctor once a month to cut the calluses off with a scalpel. I have been prescribed a skin medication Clyndamycin in foam form which has helped to manage some of the cysts. Calluses, Cysts I used to not get my calluses trimmed, but I began

to recently. It has helped a lot. The callus trimming definitely helps a bit but it does not treat all of the pain. I will still walk out of the doctor's office with some tender/painful points of the foot. The clindamycin foam I keep on hand helps when cysts flair up but I would like something better. In warmer months when I am more active, the monthly callus cutting appointment can not really be delayed at all. If it did I might not be able to fit my foot in my shoe. Callus cutting certainly relieves a lot of the painful calluses that come from walking

They have allowed me to at least manage my symptoms and lessen the pain. However it does not help everything completely. I still have pain, embarrassment. Sometimes if the foot gets shaved too low, my feet can be very tender and hurt a lot. Aside from that, the treatment itself isn't too much of a nuisance Cyst Control, General Skin Care, Callus Shaving.

James K6a Sand the nails so that they are thinner because this improves the use of the hands and makes them more sightly. Use a lot of lotion to soften the bumps on the body so the skin feels smoother and this also helps reduce the bumps a bit. Use a lot of lotion on the feet and wear quality shoes types that we have tried and tested to minimize the callouses on the feet. Our treatments address each of the symptoms that can be addressed: the bumps on certain parts of the body, the blisters on the feet, and as for the tongue we don't treat it, but it seems to be only a white discoloration and seems to work fine - he eats good and speaks well.

It hasn't changed, only to the degree that we tried different types of lotions until we found one that seems to suit him best. Very well, at least to the degree possible. It doesn't seem to stop the progression of course, it only makes the symptoms milder. Very well. Very well. This is hard to say...again, he is not debilitated, we adjust. The things that we are doing seem ideal. I would like to thank PC Project for everything they do, from testing and analysis to support programs, awareness campaigns, and generally helping everyone they can who shares this rare condition.

Jamie K17 Hot soaks for the cyst. Keep clean and dry. Trim calloused areas on feet. Sand nails Ibuprofen 800 mg 5 times a day Smoke marijuana Take anti depressants Visit a counselor

I would like to see less cyst. I just don't want to hurt anymore More frequent trimming of callouses. I have had the cyst my whole life. My parents would hold me down and try to pop them like they were pimples. At five years old they finally realize that it wasn't a pimple they did the best they could to find help for me. I finally found out in 2014 Not very well but I have no choice It doesn't After trimming I have a little more ease of walking nothing helps the cyst except after they pop it is amazing at the relief however bandages can't be place in spots so if I wear clothes they stick to the drainage and pulls it open when I move. Nothing helps Trimming is hard because I have to be a contortionist to get to the callous it affects my knees. To lessen the pain and stop the decaying of my body I would first like to thank the PC staff for all you do for us. I would like to thank the FDA and just pray that someone can help us.

Janet K16 I sand my feet every two weeks, this way I can get the "high" spots reduced and it's seems to work a little as far as walking goes. I take a prescription anti inflammatory at the risk if kidney disease. I also only wear Birkenstock open toe sandals year round, and if I have to deal with snow, like to leave work I wear a shoe called Keen, it has a wide toe box and works "in

a pinch" Pain It has improved, it got better with age and wisdom. Now I know don't let my feet get too dry so I don't have cracks in callous on my feet and too moist harbors infections, I used to use a straight edged razor but getting older now and having a few arthritis pains in my hands it's harder to get the leverage needed to trim the callus with out taking too big of a gouge at a time, that is why I move to the dremel for sanding, also since I don't trim with a razor anymore I don't seem to have those bleeding nerves or what ever they are called. The dremel doesn't seem to do that. it get's me by but it just a temporary treatment they don't stop the progression it that's for sure and I'm not too sure if anything is slowed, my treatments are only masks or band aides to the pain. Well, my prime time for walking in approximately the 2nd to 3rd day after I dremel my feet. I can spend time standing on the lawn longer to throw the ball for my dog or walk around my yard or garden. my treatments remain the best so far and I've been doing this regime for over 10 years My Health! The prescription pill, I've taken for half a life time (Voltarin 100 mg 1x da) I have to keep close tabs on my kidney function, my lab work shows through the years a decrease in my creatin levels and my Dr wants me to not take this medicine but I simply can't function without it so I'm gambling and taking that chance that it won't debilitate my kidneys to the point of needing dialysis. It's a crap shoot to be quite honest. something to releive/stop the pain with out putting your whole bodies health in jeopardy

Jean K6a Podiatrist every three weeks. Keep off my feet as much as possible, I am very lucky in that I have a very supportive husband who is my 'feet' Hard callous removal and filing of toe nails (I file my own finger nails) It hadn't changed It keeps the callouses under control although it is painful for a couple of days after the treatment It doesn't stop the symptoms or slow it down It helps a little but I still can't do anything that means using my feet for any length of time The condition hasn't really changed The feet are sore after the treatment and hurt for a couple of days Pain relief, thinner nails and no callouses(in that order)

Jeff K16 Cream on my heels to reduce cracking and anti inflammatory drugs, Statin , always wear shoes even in the house. The pain from deep cracks in the heal and reduce the pain. The discomfort of walking on hard surfaces. Internet has given me better options for creams and information on what other people are doing that works. Doesn't heal the cracks that are there already and doesn't stop future cracking. Doesn't do anything to stop or low the progression. Has reduced some of the pain. I always wear shoes in the house, It makes life closer to normal. Still your feet have that callus smell. To much cream makes my calluses mushy and stinky. The heal cracks break off and smell bad. ease the pain and reduce the crack heals. Cutting your self as you use a utility knife blade to trim them, The dust and smell of trimming your calluses with a dremel.

Jo K6a Flynn has had a trachyostomy before so we see a specialist every 6mths. We visit a dermatologist every year. We see a physio when required. About to visit orthodox people. We see a podiatrist every 4-6 weeks. We have a bleach bath 2x week. A salt bath every night and apply heal balm and betadine to effect areas every night. Callus thickness. Nail thickness. Never used to be every night. Flynn has aged and become heavier and more active. Boy first - everything else second It helps ease some pain - we think They don't

really If we could see a podiatrist every day during summer that would be cool They are working for now By the time 4-6 weeks roll around the calluses are big again

John Paul K16 Paring callous down weekly Trim nails weekly Apply diy CBC salve to feet daily x2 Prescription bupropion patch weekly OTC Tylenol and Advil daily as needed Medical marijuana as needed Pain Growth rate Appearance and functionality Harder as I get older to manoeuvre and nails get thicker harder to trim. Painful I get by, that's about it I have nothing to compare to, it slows it I think but never stops it I get by, but I do not thrive by any means Same The fact I even have to do them Reduce or eliminate pain Increase functionality Improve appearance Please help us

Johnny Junior K16 I am currently shaving callouses on hands and feet, applying CBD oil to hands and feet, wearing specific shoes, filing down nails on hands and feet. Counting and calculating all steps. Dry crack fissures, appearance of nails on hands and feet, reduction in pain. The treatment changed due to age, activities, and weather. These factors increase the time that I have to treat my symptoms and the pain. The current treatment regimen treats the callous' and nails. Mostly asthetics for hands and feet which reduce some pain.

The treatment does not really slow or stop the progression, it simply assists in the upkeep. These therapies allow for me to walk, stand, and use my hands a bit longer throughout the week. Some days it does nothing. These treatments have worked the same. There is no real change because there are no real answers or methods. We just live par for the course. The most significant downsides to the current treatments is that at times after upkeep my hands and feet are extra sensitive and I have to be more careful with every move for the next day or two. If there is no complete cure, we would like to see a big decrease in pain and in callous formation. I once used a tea of Papaya leaves and Neem leaves that after a week of drinking, peeled almost all the layers of callouses off of my hands and feet with no pain.

Jorge K6a Trim callouses and cut and sand nails thick nails in hands and feet and hard callouses in feet beeing able to stop the thik nails from keep growing thick

Joshua K6a Using a dremel to trim nails, smoothing out callusses on feet with an egg ped Thick nails and callusses on feet More time is needed to work on feet Only helps moderately. My nails and callusses are too thick It doesn't. I have extremely thick nails. So difficult to trim down Interferes with my ability to walk long distances and run in cross country Remained the same It takes time Finding relief from foot pain None

juan K6b tomar medicamento neotigasol 25 mg una pastilla cada 2 dias (acitretina) dolores y menor crecimiento de los callos menor dolor algo mejor

Julie K6a Dremel feet regularly. Calluses Stayed same Reasonably well. Fairly well if done regularly. Well Well Takes time need to do often. Improvement of calluses.
No

Julie K16 my son sees a chiropodist every 3-4 weeks. we've encouraged him to shave his feet down every evening and apply cream and also to change his socks at school as his feet get sweaty and hot and this makes his PC symptoms worse. keeps his calluses from getting too big. it hasn't. it doesn't stop the pain, it's more about maintaining the level of the callus. they don't they don't really. there has been no change we have had to push hard to have regular treatments and sometimes depending on which chirpodist we see they are reluctant to book us in again so quickly. But if we don't see the chiropodist regularly we really notice a difference in my son's feet. The other downside is that he has to miss school and he doesn't like this. I don't want to complain though as we are very fortunate to have the options to have treatment for free. anything to stop the pain!! no thank you.

Justin K17 Currently, all I can do to manage my condition is to use a 9 blade scalpel to shave down the calluses on my feet. The calluses on my feet and my nails. I now have to be more on top of my treatments and perform them more often. On a scale of 1-10. One being very poor and ten being very well. I would say 5. They do not slow the progression. They simply make my feet look less ugly. The pain still resides. These therapies are mostly for aesthetic purposes. They do not really relieve symptoms. Over time as I have aged, I have noticed that I have to shave my calluses more frequently. The most significant downside to my current treatment is that it is a reoccurring process. I have to continuously keep up with it and denote at least 40 minutes each time I spend working on my feet. In an ideal treatment, I would look for a product that would reduce the likelihood of cysts becoming inflamed. The more inflamed cysts I have, the more at risk I am of potentially fatal infections. They also develop in the most inconvenient locations on my body. This forces me to always be to adapt daily to a new growth on my body. PC causes great pain. Because of this patients are forced to take over the counter pain medication more than the recommended dosage. Certainly, this will potentially have poor health consequences in the future but we have no way of dealing with the pain without them. Maybe a safer over the counter pain medication that still remains effective would be of use.

karemK6a use urea When she was born, she did orofacial therapy to be able to feed her while she was sleeping thickened nails prevents thickening Fairly well
I feel it is very important to help the newborns because the doctors do not know the disease and when they do not understand it they do not know how to help the baby. My daughter went through a number of difficulties to increase their weight due to the pain caused by drinking milk

Karen K6b Removing calluses & hard skin. Wearing Sketchers shoes as they have memory foam insoles which helps cushion my feet Calluses & hard skin build up. Plus the pain resulting from these conditions Self managed rather than visiting a podiatrist due to cost & a lack of understanding of PC on their part Reduces the pain slightly but only temporarily

when removing calluses. Not at all - the treatments just give temporary respite from the pain Wearing Sketchers shoes enables me to walk more than if I wore other shoes My condition has not changed Removing calluses is painful in the short term. Sketchers are great for daily activities but I cannot wear fashion shoes (ie: high heels) as I cannot bear the pain Total pain relief that focuses on my feet!

Karen K6a Applying lots of creams, seeing podiatrist and specialist clinicians. Painful callouses and fissures on feet. It hasn't. Not well. Not at all. Not well. Not well. Time consuming. Better treatments for management.

Karen K17 Nothing for my son as he is too young, my husband does a lot of stuff himself as described in previous answers Cysts all over body and calluses on feet My husbands calluses have gotten worse with age.O.K but it is an on going thing It doesn't stop or slow it down it just helps to control it best he can My husband is a personal trainer so he has to manage his feet all the time and the cystsJust the same they work as well as they can with no cure for this illness, the cysts and calluses always come back so he has to maintain the care he does for his symptoms throughout his life, just more as he gets older They don't work permanently, he has a lot of pain lancing the cysts, they leave scars and eventually come back, he is in pain most days either with cysts or the calluses on his feet To reduce the cysts permanently and something for calluses no

Karmyn K16 I use a sander to sand down my 5 year olds calluses. I do not feel comfortable cutting them with a sharp object. I also must sand down the ends of his toenails before cutting them. I apply salve on open wounds. If I do not stay on top of sanding down my 5 year old's calluses, they crack open into deep painful fissures that prevent him from walking.

Over time as my 5 year old has gotten bigger, his blisters / calluses / fissures have increased in number and size resulting in greater time needed for care. Not well as pain free days are non-existent resulting in reduced mobility and quality of life. Not well. My son's symptoms have increased in severity as he has grown older. Not well. My 5 year old is unable to fully participate in sporting activities similar to his peers.Not well. My 5 year old's symptoms have increased in severity as he has grown. Time spent on care that does not fully treat the symptoms (painful blisters and fissures). Lessened pain.

Kate K16 I have to trim the calluses to reduce their build up, there is a balance as if too thin then very painful and if too thick seem to get more blood vessels/ nerve bundles. I apply vaseline to my feet which seems to keep the calluses and skin where joins calluses a bit more flexible. callus build up with trimming, and vaseline used for prevention of fissures/ cracking of skin changed very little, have tried many topical medications from specialist dermatologists but vaseline works best for me Very minor impact on pain They do not stop/ slow progression very minor impact effect of treatments unchanged over time I do not mind having to trim the calluses or apply the vaseline, I am used to it. The big downsides are their limited impact on pain reduction. Reduction in pain level and ideally reduction in size of callused areas

KATHLEEN K6a I try and rest them most nights. I see a podiatrist every month and I use my scalpol inbetween. Sometimes it levitates the pain. I have used different creams etc before but I didn't find they helped so I don't have any treatment now. Very slightly relieve the pain. Removing the skin slows the growth. Sometimes very well but others not. Everyday is different. They are still the same but have helped. I only use the scalpol and sometimes cutting yourself is the downside. Something to help the pain so I can walk for longer. Kathleen K6b use a Ped Egg-does a good job of sanding down calluses and helps feet feel better. Soaking feet with Johnsons foot soap also helps feet feel better, and also helps to keep feet from sweating so much. Callous and nerve pain, and foot soreness. My treatment regimen has not changed as this is the best way for me to have much needed relief and comfort. Pretty well, unless I have been on my feet for a very long time. Then I would need to get off my feet and elevate my legs and feet. Pretty well, but they are only a temporary fix. They are a big help. They work well. I have to make sure I do these treatments on a weekly basis. Otherwise, my feet will start being uncomfortable. Treatments that would eliminate all pain and keep feet comfortable so that walking and standing would be enjoyable on a daily basis!! I am hoping for the day when there is a cure for all P.C. Patients!

katie K16 shaving off the excess skin with a blade while i am in the bath about once a week. also the tips of my fingers need shaving once a week and both require filing after to smooth excess callouses need to shave skin often..appears to ve growing faster keeps it under control..looks better and less painful very well very well very well well have to find time once a week to do treatment unsure

Kerry K16 Debirdement only, from podiatrist and self Appearance, usually less pain when trimmed Need to trim more regularly Pain, a little but not really a treatment for pain Not at all A little, usually feels better after treatment but pain still there, and varies widely As above, not that well Cost of podiatrist visits. Reduce the foot pain, and allow to stand barefoot, and walk further without pain Reducing pain for me is way more critical than ant appearance of treatment regime change. Also nails are a secondary concern as they are not (for me) painful

Kristi K6a Using a dremel to sand down calluses And thickened skin on feet, hands, knees. Use cutters to pop blisters and cut other areas of callus or nail. Calluses, blisters, cyst, follicular hyperkeratosis, leukokeratosis, thickened skin Have to be more diligent about keeping them managed It helps make it manageable on most days Not very well, it's a daily regimen Keeps the calluses from rubbing as much on shoes but sometimes makes it more sensitive that the rubbing causes more problems. For the follicular hyperkeratosis - the ones I remove - helps them from hurting. Leukokeratosis - brushing tongue pretty hard every day helps manage the thickness. About the same / helps manage but doesn't completely help The dremel causes more blisters especially when I cut down too far. After I grind my nails down I usually have about 3-4 get infected over the next few days. Something to manage the symptoms that cause the pain- blisters, nerves sticking from calluses, follicular hyperkeratosis from developing as severe, leukokeratosis from being thick where I can taste normal, allow me to walk long distances and not miss out on family outings I had my

daughters nails removed and they have never had infections of the nail since. That had been 8 years for my 11 year old and 4 years for my 8 year old.

Launie K6a Cutting off callus/corns Lancing (removing) infected nails and cysts
Pain None Cutting back callus makes walking less painful None This question is redundant. Same They take a lot of time There are none. It's a gene. My hope is that folks with PC will quit trying/using every snake oil that is recommended by the "magical thinkers" in our community and accept the fact that they are wasting their time and money. It seems few understand genetics. Until the gene can be engineered that changes us, we are not going to be cured.

Laura K6b Managing the calluses by trimming. Trying to stay off feet as much as poss. Taking painkillers - ibuprofen or naproxen. Pain Have to take more painkillers now Not well, all very temporary. Painkillers only dull the pain they dont get rid of it. And only lasts an hour or so max. They dont Only moderately Theyre not coping with the increased pain Painkillers are bad for internal organs, that worries me. And they are only a brief respite Pain reduction and appearance improvement

Laura K6a Wash feet with antibacterial soap, trim calluses at least once a week, file down toe nails, elevate feet when pain is severe. Sometimes apply aquaphor or vaseline to dry feet. Odor and pain a little Added odor control soap because odor became to strong for soap to address. Not at all. No real pain subsidence, very minor after callus builds up and is cut/removed. They do not stop or slow. It is persistent. It goes from bad to worse but is never really good. They do not improve anything. These are not treatments, they are best practice measures to make it more manageable but never relieved fully as would be expected from treatments. I can cut myself when callus scrapping resulting in bleeding. The soap does not stop the odor, only temporarily removes. Something to help keep the foot temperature cool and less sweaty. Also something to help with odor and bacteria production. No, but please help pC patients. If you can help with pain management and help with walking better, please do. We need support for our rare disease. It doesn't actually kill our bodies, but it attacks our spirit every day and that may be worse than death.

Leena K16 Pedicure. Limited walking (easier now when retired) Callouses, thickened nails. Not much, about 30 yrs ago started taking Neotigason. Meet my doctor once a year. A bit In scale 1-10 about 2 A little, verran little In fact my condition has not changed You know the risks of Neotigason Painfree feet I feel confident that my grandchild can benefit pc project's wonderful work.

Lewis K16 Trim my calluses about once a week. The size of my calluses. No It helps a little, but I still have Pain. It doesn't stop the disease. Enough to allow me to play golf. It has not helped. The pain after the trimming of the calluses I have a lot of pain for about two days. Some great arch supports that would relieve the pressure points on my feet. No.

Lindsay K6a I had my fingernails removed and just have little bits of fingernail left that I sand down flat. I use a tongue Scraper on a daily basis. I file down my toenails. I use a electric dremel tool to sand off calluses on my feet. And I use various types of nail clippers to groom the calluses on my toes that are too painful for the dremel tool. My fingernails hurt less when sanded down because they were removed and how they grow now they snag on everything more if not filed down. I scraped my my tongue because of cosmetic reasons to get to white growth off my tongue. Sanding my calluses with a dremel tool improves foot pain and can somewhat prevent blister growth. Also when I sand my calluses down my feet look better and are less embarrassing. When I was younger I used scalpels to cut off my calluses but I found that sanding them with a dremel tool felt better and make a left a better-looking. Other than that I haven't really changed how I care for my calluses cuz I've had no need to I get good results with the dremel tool. My most significant symptom is pain caused by calluses inflammation and blistering of the feet. Sanding down the calluses with a dremel tool makes a surface of my skin feel less tight and painful and will somewhat stop blisters. I think sanding the calluses gets rid of the tight pain feeling and then I walk better and will get less blisters.

Sanding calluses and fingernails makes them less thick cuz they're sanded down. But it doesn't stop the growth or lessen the grows it still grows at the same rate. Sanding my calluses causes less pain I am able to do more activity with a little less pain. Sanding the calluses gets the same results over time but more surface area is continue to grow calluses as I age. My current treatment doesn't actually stop or slow down the progression it just makes the calluses less thick and the sanded areas. The on-site injections to limit callus growth.

Linnea K16 Cut, trim feet. Tried many things over the years and this is the only thing that was effective enough. Temporary pain relief, and also pain reduction. None reallt because nothing else works. It's why I do it, to relieve the pain as much as possible. It's like putting a bandaid on an open wound. It kinda helps, but there's more that could be done to make it better. Can increase productivity to moderate amounts at best temporarily. About the same Take up time. I need to schedule time when I can fit it in. Pain reduction/elimination first and foremost. Cosmetic improvement second choice, but maybe they go hand in hand.

Lisa K17 Bleach bath, I have learned to do my own incision and drainage of abscesses since I get so many so often Cysts No Not st all. The reoccurrence is terrible Not at all. Just make is mildly tolerable Not at all. I miss work regularly and often can not attend social situations due to pain Not at all Not aplicable Minimize the cysts None
Lorraine K16 Trimming and filing callouses and nails on feet. When cysts become inflamed, I use topical or oral antibiotics, and lance them when needed. I take paracetamol and pregabalin daily for pain. I take CBD hemp oil daily for pain and inflammation. I use Epsom salts and tea tree oil in baths to reduce chance of infection Pain in feet, growth of nails and callouses, inflammation, reducing infection risk, treating infections when they do happen
It becomes more time consuming over the years, as symptoms increase It only covers the tip of the iceberg. It does not stop or slow down the growth of callouses or blisters, it makes very little difference in pain. It's a lot of time and effort for a relatively low impact, it just lets me make a small difference to my daily life, as to stop treating it would make it impossible to

walk They make little to no impact on progression, it just removes the outermost layers of callousing, as the raw skin inside starts to dry out, it continues to grow. Once it grows again I have to cut it back again, it's a simple maintenance cycle, it has no lasting impact They don't make a great deal of difference, the main difference is keeping the callouses more even in depth, so they don't grow too thick. If they become too thick, they outside becomes very dry, and the inside becomes more moist, both of which cause more pain. To keep them regularly trimmed stops them getting too soft or hard, too dry or soft These are the only things that have worked for me, so I haven't changed them too much Painkillers cause side effects, like fatigue, and over time can cause damage to the liver etc. Trimming callouses is time consuming and the results don't last long, and after the callouses are trimmed my feet are far more sensitive and painful, making it more difficult to walk Reduction in pain would be one of the most significant possible changes. A reduction in growth of nails and callouses would make it much easier to deal with

Junghwa K6a Just after trimming nails, It looks close to normal nails and he can use fingers without barriers and wear socks and shoes with comfort. Just after trimming nails, It looks close to normal nails and he can use fingers without barriers and wear socks and shoes with comfort. he don't like the trimming. I think it cause some pain. so it takes so much time. I should show some animations on YouTube during trimming. maybe some fake nails.

Lydia K6a Trim callus with two sided razor. Go to foot doctor to trim nails. Callus. No still the same. it doesn't. Again, it doesn't. Nope, doesn't. Doesn't Ease pain

Lynda K6b Trim the calluses and wear sensible shoes Painful feet Trim more often because they seem to need more trimming these days The smaller the callus the less pain Do not stop or slow it. Sometimes a callus will go away, but another will soon take it's place somewhere else on my foot I am able to be on my feet for short periods of time if I trim every week They don't work as well as they used to as it is difficult to trim a lot without bleeding Takes time, but it is just once a week so is manageable An easier way to trim the calluses. And more comfortable shoes No

MaÅ,gorzata K6a I go to podologist twice a month and to physiotherapist, I uses cream, mists, sprays to care about my feet, I cut and polish my nails. I buy soft and breathable shoes. To reduce my calluses on my feet. It chanhge about 7 years ago when I found a podologist, who also help me how to care about feet at home. Also this year I stardet to go to physiotherapis who massages my legs from feet to ankles which reduces my tension. It helps not to make them bigger. My nails are not growing as fast, also my calluses aare not as big, but i cut them every two weaks. It makes my live pretty norlam, and I am able to go to a normal school, and do some activities, but in limited time. My conditions are pretty the same, and when sometnig changes I also find a new treatment. The money aspect, and time I have to spend on it. Something that will reduce the pain

Michael K16 I try to keep the foot calluses trimmed. Sometimes I apply creme to the heel cracks to soften them up. The problem with the deep cracks is the hard callus crack stabs the original skin, making it feel like you are walking on a razor blade. A cream can soften the hard callus. Keeping the calluses trimmed allows your feet to stay consistent so you can manage the disease. My treatment is basically the same as it has always been. My current treatment of trimming the calluses allows my feet to function as normal as possible. If the calluses get too thick they are just as painful as when you first cut them. You need to be somewhere in the middle. My progression has been limited. The calluses that I have now are the same calluses I had as a child. Like I said earlier if you keep the calluses under control you can manage your day better. My condition has not changed drastically over the last twenty years. Other than trimming and maintaining the calluses, I've only used vaseline to treat my heel cracks. Although the vaseline helps soften the cracks, the cracks do not grow together. The cream helps to keep them soft while they thicken. Once they are thicker you can walk better on your heels. A cream or solution that would permanently close the cracks. During our meeting in Maryland, I was astounded by the number of people that were using a pain medication to alleviate their pain, some even using opioids. That is not ever a solution to this problem in my opinion. The cure would only come from a stem-cell treatment. Our skin cannot function normally due to the cell structure. That is not going to change. I would be happy for a cream or ointment to help me control when the skin gets taut or some other topical solution to heal my heel cracks.

Michele not known Cutting off and filing calluses. I use tweezers to remove skin under and around my fingernails. And I also use them or other tools to remove... Whatever it is that grows under the nails that causes nails to be too thick. I use a lot of lotion. Reduces calluses and the pain and uncomfortableness associated with it. As a kid I suffered. As a teen I figured out you can soak and use blades. At 33 I quit spending money on products that claim to heal it. Some products actually make it worse! And I'm getting better at knowing when to stop scraping a filing because too much can be even more painful. Not well enough. Sometimes I wonder if it's even worth the trouble None Mild The same? Too much creates this thin brittle layer that results in many cuts and it essentially feels like you've removed all the skin. Something that makes my management of my condition a hell of a lot easier and convenient. No.

Michelle K17 Trimming nails regularly. Regular baths/ bleach baths. Diaper cream (butt paste) skin is very sensitive. Antibiotics as needed and mupirocin ointment for nails and blisters as needed. Cera Ve SA lotion for bumps on skin. None of the treatments help the symptoms go away, they just help with flare ups or infections such as with the nails, cysts or blisters. We've had to add more because she's gotten more symptoms over time. It just helps with flare ups and infections but nothing ever truly goes away or gets better. They don't, they just help clear them up until they come back or she gets more or they get worse. Hard to say as she is only 17 months old. They help to manage it but it is still a difficult condition to deal with on a daily basis as it never goes away and it's hard to determine when or if my baby is in pain. Also her condition has gotten worse as she has developed more symptoms. The downsides are that they don't completely take away the symptoms they just help to manage

flare ups or infections. Something to help with pain and something to help with time it takes to care for symptoms such as nails or cysts and possibly even cosmetic improvements for nails. I'm thankful that the FDA has listened to PC patients and hopeful that they find some good treatment options if not a cure.

Miranda K6a I trim & pare down my calluses after soaking in epsom salt. I use corn & callus remover pads. I have used urea cream on occasion. I receive bi-weekly pedicures. I try to smooth my calluses as close to the skin as possible because I then feel much less discomfort. I also try to improve the appearance of my feet since wearing sandals is one of the best ways I can minimize callusing. Yes. I used to do callus maintenance as needed, now I do it every week no matter what. And, I never used to get pedicures because of the embarrassment of another person seeing my feet - but, now I don't care about that as the visual look of the nail is so much better than anything I can do on my own. It works pretty well, but there's still a lot left to be desired. They don't stop or slow it. It's purely maintenance. They allow me to be able to run a few miles and walk reasonably well. The routine I have now is the best I've managed my condition. The most significant downside is the amount of time required.

A quicker way to manage callusing and visual improvement of the feet.

Nathalie K16 Cut Mal aux pieds Je prends des dafalgan quand j'ai besoin de marcher un peu plus dans la journée M enlevé un peu le mal de pieds - -
- - Ne plus avoir le mal constamment. -

Nikki K17 Pain relief and antibiotics when cellulitis occurs. The cysts and abscesses are spontaneous I can't stop them. I tried all avenues with help of Dr Edel O Toole Pain, avoiding blood poisoning Because the condition has worsened and the regularity and severity of abscesses gotten much worse it takes longer to clean, dress, drain them and deal with daily personal hygiene and readying for each day. More facial make up needed too and clothes that hide. Not well. No alternatives They do not. None They can't. They don't It's a case of the only management available for this difficult condition. I have to make do as no alternatives The pain, the mental effects, the tiredness and depression Pain relief that didn't cause other symptoms and problems I don't agree with using animals in experiments and as such I feel really guilty that I want better treatment. Animals are not on Earth to be a commodity we cause immense suffering, distress and death and that we use for our own ends. I cannot countenance any cruelty to animals just because I have a bad condition. I'd rather struggle with a clear conscience.

Nykole K17 Nothing, but losing weight to keep pressure off my feet. Cysts, trimming callouses, filing down thick nails. Hasn't changed any. It keeps callouses shaved down for 2 weeks until next callouses shaved down, and cysts, don't really have a treatment regimen. Just go to the ER or Dermatologist for lancing or sac removal of cyst or boil. Just manages it, not treat or stop. If a cyst is landed it takes about 3 days until it heals up a bit before I can be active and not in so much pain. Shaving the callouses down every two weeks keeps it from having excessive buildup, and relieving added pain to the underlying skin since callouses are really hard. Just manages it. It takes really long when working on feet so it kind of has to be planned and set to take time out to trim nails, shave callouses, and when

Dermatologist is closed, having to go to the ER to have cysts lanced can be really annoying since ER doesn't know a thing about PC, and they try to say that cysts are due to staph or Hydradenitus Suprativa. A lot of misdiagnosis, and sometimes they're not understanding and want to give pain medicine instead of doing a direct lancing. And children have not enjoyed having nails trimmed or filed since they're so thick and somewhat painful during nail cutting or filing. Pain resolve, and lessen cysts, and clear up dark marks. I have read an article on Gene Editing in 2017, and I still have it in my email, and wondered if that would be considered or thought about regarding this condition.

Flinn K16 I trim/cut my calluses on my feet twice a month. I have tried doing it weekly and it is painful. Every other week leaves my calluses at the right thickness. Some people in my family use electronic sanders every morning, I have tried it and it doesn't help. I work on my feet daily and my current trimming schedule is the most effective Calluses on my feet only. Toes and footbeds are completely covered in calluses. Toenails are in mostly good condition, thickened pinky toenails need to be cut with clippers I used to use a high powered dremmel tool to sand down my calluses. It took too long and caused damage to my un-callused skin on my feet. I am now using a razor blade corn cutter takes about 30 minutes and I can do it quickly and effectively Trimming my calluses every two weeks helps keep them from cracking and/or splitting. I can control the thickness. I don't trim for pain relief; often my feet hurt more after trimming. The extent of my calluses has been steadily increasing for approximately ten years. Sometimes trimming helps with pain and I can do more activities. Other times my feet hurt more after trimming. It's hit and miss Using a hand held corn cutter is my preferred method. As my calluses increase in extent I continue to trim the same way
 Trimming can help with pain or trimming can make my feet hurt more. It's sporadic
 I would love to see a genetic solution so that I can be assured that my children aren't born with PC

PAMELA K6a After 6 months, in my hospital, I sedate and inject botox into my hands, feet and armpits. The blisters and how I cut the hyperkeratosis, calluses go down a lot and the pain diminishes a lot Before I tried local creams but without success My dermatology has known from the first moment the symptoms and botox treatment I injected it with success Botox has an effect of approximately 6 months Before I lose effect and have to reapply, I can stand longer and walk painlessly, make physical activity plans longer than usual without treatment Yes I have to go through the operating room every 6 months I could walk without pain, in summer I do not have that burning sensation all the time. Eliminate the pain!

Paolo K6a At the moment nothing other than living within my limitations as much as possible. Pain and infections. I tried Neotigason for some time but I stopped because I had no real improvements of my condition compared to the collateral effects. // //
 // // // A way to feel less pain and to get less infections.

Paul K16 None None Hasnt Keeps in check Do not Allow me to wear road cycling shoes
 Havenot None Slow growth No

Philip K6c I take Ibuprofen regularly and use a moderately greasy emollient to stop the calluses becoming stiff. Foot hyperkeratosis pain. I've only been taking Ibuprofen for about three years after hearing about it from other people with PC. The Ibuprofen has a significant effect mainly on my feet's ability to recover from walking. They don't. They allow me to do a bit more, say 10-20% than I would be able to do otherwise. N/A

Ibuprofen has potential side effects taken long term, particularly kidney disease and stomach ulceration. Nothing so far! Less pain allowing me to walk more particularly in warm weather. I think there's a real chance that topical Sirolimus will be helpful

Polly K16 try to trim on regular basis and not just when calouses hurt - use straight razor and dremel tool. calouses on soles of feet. hasn't changed since childhood - my mom had PC and always trimmed my feet with straight razor - i started trimming my sons feet as soon as he could sit still. has seemed to work for us. trimming is just a way to manage. get some relief after trimming. same as abovenov downside - what i've always done anything to relieve the pain

Rachel K6a I trim my calluses about once a week. I pop blisters to relieve pressure whenever I have a blister. This is done multiple times a day. I trim my nails about once a month. I normally take ibuprofen 3 times a day, but I'm currently pregnant so I'm not taking any pain medication. As a result I'm in much more pain and walking/standing even less than normal.

Pain. Popping blisters often gives immediate relief when my foot is throbbing. The ibuprofen helps make the constant dull pain more bearable. They do not seem to stop or slow the progression. If I don't trim the blisters will get worse, but if I trim too often I get more blisters. Taking ibuprofen allows me to do my job with less pain and allows me to have more of a social life by helping me walk further or stand longer. I take more ibuprofen than when I was a teenager and in my 20s. It is sometimes difficult or embarrassing to find a place to take off my shoes and pop a blister. I worry about the impact on my overall health of taking ibuprofen so frequently. Something that decreases the pain significantly so I can walk an average number of steps compared to someone who does not have PC.

Randle K16 Trimming and oiling calusses. It addresses the growth of the calluses, the cracking of calluses, the pain related to having calluses and finally it allows my feet to fit my shoes. It gets more intense each year as the growth of callus expands on both hands and feet.

Ok but not great. Not. They make it tolerable. Not. The time and pain involved it brutal. Easier Removal of the calluses and pain.

Rebecca K16 Trimming calluses and nails, taking fluconazole for thickened nails, taping feet with athletic tape. Calluses, cracking and bleeding in calluses, thickened nails. I started taping my feet all the time because the cracking worsened, and started taking fluconazole once my fingernails started thickening in college. I think it's the best available right now, although the time it takes to keep my and my daughter's calluses trimmed is pretty extensive. Not at all. It's a constant battle. Without doing what I do I don't think I'd be able to walk at all or participate in any of the active things I like to do. I think we've figured out what the best available ways are to manage it right now. They don't change or eliminate the calluses, and they don't eliminate the pain felt with every step, just make it

manageable. It's sad to not be able to wear the shoes I want to wear, and I'm sad that my daughter will have the same thing, and have to go through feeling the acute embarrassment of the early teenage years and not fitting in with shoes, etc. Significantly improve a way to manage the calluses, both thickness and cracking, and improve thickened nails, but mostly to manage or eliminate the pain of walking with the calluses.

Renee K16 I currently trim my feet with a GEM #2 razor blade. I then use a foot sander to make them smooth. After I have sanded them I put on Corona Ointment and socks. The calluses must be trimmed because the bigger and harder they are the more pain I am in. If the calluses are cut unevenly each tiny ridge will cause pain when walking. I then use the Corona Ointment to help soften and heal the area I cut. The day after cutting calluses my pain is much less if I use the Corona Ointment. My treatments address the appearance and size of calluses which then helps decrease the pain a small amount. I added the sanding and the Corona Ointment in the last 5 years because I was trying to find something that worked better. My current treatment regimen does not treat my most significant problem at all and that is why I am part of the PC group. I want to find a way to stop or greatly diminish the pain. The treatments do not stop or slow the progression of my disease at all. I must wait 3 to 4 days after working on my feet before they feel a little less pain. The 1-4 days directly after cutting my calluses are extremely painful. After the 4th day I am usually feeling better than when I cut my calluses. So only after a 4 days of minimal activity can I get back out and try to do a small amount of walking or standing. My treatments over time have not helped much. It takes me a very long time to trim my calluses and sleeping with Corona Ointment is uncomfortable and difficult. The downside to my current treatment is the pain and blood caused by trimming. It also takes a very long time to trim the calluses, anywhere from 45 mins to 2hrs. The thickness and the dryness make a huge difference in how long it will take to trim the calluses. Greatly reduced pain. Walking barefoot are in stocking feet is not an option for someone with PC. I have to use flip flops when I shower. I wear running shoes in my house all day long. Walking on a hard surface in bare feet or stocking feet is excruciating. It would be so nice to be able to walk bare foot.

Richard K16 I trim my callouses and fingernails on a regular basis I find that keeping everything trimmed, there is less pain in my feet and the fingernails do not look so bad. My treatment regimen has not changed over time. It takes a bit longer now as I get older Reasonably well They do not stop or slow the progression. They do not necessarily improve my abilities to walk,, etc. They have kept the physical appearance of my body at a somewhat constant level It is starting to take longer to look after my callouses and fingernails as I get older An ideal treatment would be to try to reduce the build-up of callouses and to reduce the pain No

Robbyn K17 Botox and trimming Pain and length of time on feet Had to start Botox at age 26 as it got too bad. Botox yo feet every 3 Months. And scheduled trimmings every 4-5 days. Fairly well. Treats it 80% of the time Botox works the best Even seems to reverse the extent of the disease- callouses are less and some are gone Very well Still working but still have break through blisters or open sores from time to time Botox is Very

very expensive And extremely painful to have done Trimming is time consuming Look further into Botox/ Increase dose And look into surgery to cut my sweat glands to my feet

Robert K6a Taking care of my feet Callous growth. Went from a podiatrist to doing it myself It keeps me walking It keeps me going Hahahahaha I'm still walking. It's not that big a deal. Pain relief.

Robert K17 Walk less. Use of soft insoles Use of Painkiller's Lessens the pain I feel when walking. I have had increased my strength of painkillers. As I now need stronger pain relief The painkillers reduces the pain very slightly and allows me to function during the day. It does not stop or slow down the disease at all. Without the pain relief I cannot do anything. Increased strength of pain relief to manage disease. Continued use of pain relief has had to be increased to be able to manage disease. The pain limits my activities at work and leisure Better pain relief with the need for many tablets every day.

I have my cysts removed from time to time this helps with them increasing, as I now have them all over my body. The most uncomfortable place is my scrotum and wearing underpants.

Robert K6a Pray. minimize my walking trim calluses and debride dead skin every morning and evening. apply ointments to address infection and inflammation. trim nails regularly. calluses and inflammation of feet. often swollen and inflamed. changes with condition of feet. if feet are dry and cracked then apply lubricants. if red and weeping then apply antibiotic ointment. wear supportive shoes and socks. temporarily. generally the pain meds last for up to 3 hours. treatments maintain and prevent infection but do not stop the disease or even the extent of the feet affected. getting my shoes on. standing in the shower. maintain composure and avoid irritation. treatments are temporary I am still investing the same amount of care now as I did when I was younger. downside is the treatment is temporary. I still treat my feet as often and long as I did when I was younger.

minimize swelling and inflammation stop the pain of feet I appreciate the efforts of PC project and the dedicated and caring people who are aiding patients.

Roseann K6a Debridement of hands & feet, excise cysts, clean wax from ears, build bones in feet. Build up of calluses and nerve exposures which cause pain debridement of hands and feet have not since i was born, the painful cysts presented in my 20's and continue now where they must be surgically removed It maintains, not pain relief as it's a balance b/t too low or too much growth It doesn't, its only to maintain The therapies and meds only allow me to be a functioning productive member of society but never negates the pain and exhaustion They maintain my existence They only maintain my mere existence; they do not provide any significant pain relief Better quality of life where I could do more pain-free and not be such a burden to those I love and who love me I know there are far worse things in life, but for me/my life, this excruciating debilitating pain, awake or asleep, is exhausting.

Roxanne K6a Healthy diet, exercise and homeopathic tinctures/oils, cycling acupuncture. Overall well being and mental state. I would use more advil or ibuprofen, but

didn't want to ruin my liver. Does not. Does not. Does not. Better eating habits alleviates the symptoms of leukokeratosis None Oral medication that inhibits only the mutated keratins from multiplying and manifesting in my thickened nails and tongue. No.

Ruben K16 I trim the calluses on both my hands and feet with a razor blade. Cutting deep enough to remove the thick layers of dead skin, but leaving just enough callus to have a pad of protection. I apply callus control cream with 20% Urea up to 3 times a week. Soak feet in a foot bath consisting of borax, iodine, and bran. Taking pain medication. Foot insoles for sneakers. Wearing thick socks. Helps with the pain and swelling. Minimizes the friction felt. Keeps calluses moist and trimmed. Absorbs the shock from walking or standing. More attention to detail. How deep to cut the calluses, so as to being comfortable and limiting pain. How much more mobility I get from using insoles. The amount of thickness from the calluses that I would cut has decreased. With the application of the urea, my calluses aren't as hard. I've learned to keep them moisturized as possible. But not so much that they are totally bland so to speak, that it's hard to stand or walk. Very little. It's a huge help from not having trimmed, moisturized calluses. Or insoles to absorb shock and lessen the impact on my feet from walking or standing. But it's very limited. I still feel horrible pain and discomfort. They slow it down somewhat as far as the trimming and application of urea go, but they don't stop it. Very little.

They've worked okay to the best of their ability, but not enough to significantly give relief. Having to constantly buy razor blades to trim my calluses. Relief is temporary. Pain relief. Increased mobility. Complete removal of calluses. Or lessening of calluses. Help us suffering from this condition find some sort of alleviation from the pain and symptoms of PC.

rylee K6a medicine pain i have to care more about what type of socks and shoes i wear and what i do not very does neither i can walk through school takes some of the pain away make me tired and itchy decrease pain no

Sabina K6a i just tried botox treatment yesterday so i hope that will bring big results about which i cant talk yet.. years before botox - i cool down my feets as much as possible, wear sneakers, cycle botox reduce sweating and therefore pain by walking
botox - does that very well reduce pain so im able to walk more, be more efficiant, do more things, stress levels are not as high anymore i would need a month to get back to that question, since i had this threatment just yesterday the most important would be reducing of the pain on the feets

Sachiko K6a Shaving down callouses, use scalpel to get harder calloused areas like where toe meets foot, using deep blue from doterra for pain, soaking in epsom salt, soaking in clorox bleach and water mixture for nail infections Blisters, callouses, pain and infection
Learning all the time from pc chat best care practices...experiment constantly with what may feel better Manages symptoms but cannot always keep them at bay. A certain amount of pain has become our new normal They just bring some relief temporarily but it always returns Temporary improvement Temporary and since condition worsens with activity just try to keep at bay and soldier on Sometimes shaving down callous too much

causes pain but having thick is painful too. Time consuming to sand thickened nails and nails are sensitive Pain relief and itch relief No

Sandra K17 Cysts- heating pad, hot bath, antibiotics and surgery as needed Calluses- soaking, filing, cutting Sore bottoms of feet - buy shoes with plush ortho support Pressure, pain, inflammation of cysts Support for bottom of feet The increased size and depth of the cysts needs more maintenance Best that we can do as my health changes I hope that stopping the anti estrogen will stop the progression of my disease. This does let me open to metastasis. At this point I am only recovering. I just want to get back to where I was before the breast cancer. Who would have thought it would affect my PC?

Satvik K17 Currently we are doing only nail trimming for my child. And i have no idea what to do with the blister on foot. I have not provided any treatment for my child. Please share some experiences of children who has specific mutation K17 gene with N 92 D mutation. So i can get some awareness to react as per the symptoms.

Selena K17 Modified food textures and choices to accommodate lack of teeth in lower jaw. Dremel sander to file down all 20 nails every 1-2 weeks. Frequent soaks in epsom salt baths: daily or sometimes multiple times a day. Bleach may be added to bath water to prevent infection in nails or skin if an area begins to look more irritated. Apply lotion 1-2 times a day. Change shoes often. Check the fit of socks carefully. Natal teeth and resultant lack of real teeth, thickened nails, follicular hyperkeratosis, cysts, plantar calluses and itching of feet.

They prominent symptoms have changed as Naomi has progressed from infancy through toddlerhood and now to preschooler. The areas of her body where she experiences friction have changed, with the soles of her feet gradually becoming more problematic. It keeps her pain free most of the time, but doesn't allow her to do some activities without consequence. We avoid hiking or situations which require walking long distances that would not accommodate a stroller. I do not believe they stop the progression. We have minimized calluses on Naomi's feet by letting her be as particular about her shoes as she wants. But that doesn't prevent them entirely. Minimally We still experiment with every new lotion we come across, hoping for something that really makes the bumps, cysts and calluses go away. So nothing has worked well as Naomi has grown and changed. They all involve time making a 3 year old sit still. We abandoned Tazorac for her follicular hyperkeratosis because she said it "burned." Sometimes I accidentally sand her skin around her nails if she moves while I'm working on them, which obviously hurts. And nothing makes her skin or nails clear, pain free or normal looking. Clear up her skin from the cysts and follicular hyperkeratosis to minimize infections and pain. Thank you for providing this platform to gather and organize information!

Sheri K16 I am now not working outside the home and not on my feet so much. I have completely burned my stomach up on over the counter pain relief, therefore have not been using pain relief for over a year. I have been only using shoes, insoles and lack of movement as control. I use inserts and ultra soft moccasins to alleviate the pressure points. Because there are not normally doctors willing to spend the time or effort to help with that and none on

the market, I have learned how to create my inserts myself with soft leather and double contact cement. I can't take Advil or aspirin because I have ruined my stomach while trying to live a "normal" life. Now limited to creams, or lack of movement. Never used opioids because of the addiction issues. Not very. Little to none. Minimally. Minimally. The pain is excruciating! There is no end in sight, I don;t want to take a strong drug. I am attempting legal marijuana in Florida at this time for pain control. It's hard to do because I am not wanting to get high, just slow the pain process. Reducing the size and amount calluses may help in less pain.

Shirley K16 Filing. Creams. Thickening. Cracks. I have a little more time to work on my hands and feet. It does a fair job. Don't know. Enough so that i can get by. They work better than when i was younger. Time is valuable. Improved appearance. Less pain. No

Srinivasan K16 Just cutting or trimming calluses and applying ointments to soften the calluses. I was on pain killers (Voltaren) but it has started negatively impacting by renal function. My creatine levels increase when I am on pain killers and so I have all but given it up for the past four or five years. They help the calluses to remain in control but nothing much beyond this. No it has not. The only change is my coming out of painkillers. It does not treat pain and discomfort significantly or meaningfully. They hardly make any difference to the progression of the disease. They hardly make any difference to my daily life which continues to be a struggle as ever. It has not helped at all. Trimming calluses helps to keep the growth under control and nothing much apart from this I have been able tsee. I would look for something that could reduce my pain and also make my look more presentable. I also would be happy it the treatment could make changes to my gait and walking style.

Stacey K6a Daily or weekly maintenance depending on the weather, how much walking I am doing, etc. I treat my calluses and nails very regularly, and deal with cysts as they appear.

It has become very regular and has not changed much in the recent decade. No new treatments have proven effective, so I stick to my routines. Moderately at best. I don't know that they stop or slow anything. Things grow, so I cut them back. These therapies allow me to do any activities at all. No treatments or maintenance on my part would mean a significant increase in pain which would LITERALLY stop me in my tracks. I have developed a fairly effective system for maintenance; I would say they work adequately, not necessarily well.

They can cause a temporary increase in pain, which can make things worse. They also can prove to be ineffective against severe sores or blisters, which is frustrating to say the least.

I would like to have a day free of pain where I am able to walk around without having to consider just how far I can go. I would like it if this day did not consist of me having to take intense pain medications. If a cure is impossible to find, it would be very helpful to have some more viable options in terms of healing up major blisters and sores on my feet. I have had sores that are so persistent that they last for over a full calendar year, and if we could at least treat those conditions my life would improve significantly.

Stephanie not known File my nails with an emery board, remove calluses on my feet with a callus removing tool. I used to use a razor blade, but I found the regular tool works better after soaking. Cosmetic for thickened nails that grow upward and not in length, and thickened cuticles. My treatment has changed primarily to the improvement of cosmetic tools for artificial nails, emery boards and callus removal. Extremely well. I am able to wear sandals without concern. They don't. Very well. Again, for cosmetic reasons. While my condition of my skin has improved as well as the calluses on my feet, the treatment hasn't changed. I started treating them with artificial nails when I was 15. Cost and fear of a fake nail popping off. Relief. A week or a month when my nails would appear normal or something to slow the regrowth of the calluses on the feet.

Stephen K6a regular trimming (monthly) painful points caused by nucleated callouses More nucleated callous spots to take care of scale of 1 (least symptoms), 10 (most), reducing from an 8 to a 5 None allows me to spend more time on my feet ok regular trimming, and occasionally trimming to deep and cutting myself. Pain relief

Stephen K6a I trim my calluses every day. I take at least 2 Ibuprofen every day, and I wear inserts in my shoes. Pain. All of my treatments are to ease the awful pain. Since I have been dealing with nerves and blood vessels in my calluses, I have had to take Ibuprofen and wear shoe inserts. My current treatments give me a little bit of relief during the middle part of the day. I don't think they stop or slow the progression of my disease at all. They only give me a little relief from the pain. They help a lot with getting through my workday which is critical to my existence. They have offered a little relief even as the disease has worsened. Taking Ibuprofen on such a regular basis has cause my stomach to occasionally bleed. I would want a drug that could help me better manage the pain of walking.

Susan K16 Visiting podiatrist every 5 weeks to shave callouses and trim nails. Using an "emoji" callous remover to sand down callouses every other night. Applying cream with urea to feet every night. The treatments keep the callouses at a manageable amount. They're painful if too thick or too thin. Also prevents drying and cracking. Not really. Not very effective. Treatment doesn't slow or stop the disease. Somewhat helpful. Sam works on his feet three days a week and exercises on machines. No change The most significant downside is that the treatments aren't very effective Something that would improve appearance and allow Sam to be on his feet for longer periods without pain

Suzanne K16 Trim callus and nails. Limit the amount of damage by limiting walking. Only wear soft flat shoes. Pain. I have no comparison.They don't.
Stop the pain

Suzanne K6a Seeing a doctor every 8 weeks to help take care of my feet and I try to limit my walking or standing time. Working on my fingernails every 3 weeks. Corns, calluses and blisters on my feet. Keeps my fingernails down and less painful. No, I have been doing this for over 40 years as it is the only thing that helps. Helps a lot with the pain and

wearing of shoes. It does not. I can walk more comfortably for about 6 weeks and doing my nails every 3 weeks keeps the infections down. The same as my condition has not really changed over the years. Having to take time to go to the doctors every 8 weeks especially in the winter and having to do the nails for about 2 hours each 3 weeks. Getting rid or diminishing the corns, calluses and blisters on the feet. Don't have any other comments except that I hope we have a cure soon.

Sylvia K16 Trimming, sanding and put ointment on them. Makes calluses smaller, less rigged and softer. It does not treat the pain at all. It does not stop or slow the disease at all. I can do more stuff that I usually cannot do. It takes a very long time to sand them and cut them off. Less pain! It takes my mommy a very long time to sand and trim my feet and I can not play with my family while they are being worked on.

Tania K6a Daily surgical wash to avoid infections. Trimming. Investigating plastic surgery options. See specialist Drs throughout uk Nail thickness Nail infections Feet blisters when occur Some Doesn't just attempt to manage current symptoms day by day as they occur Same as previous Just guess work. Nothing specific. Just doing what we can to manage as this happen No effect on daily life. No pain No infections Normal nails

Tate K16 Cutting calluses off with a razor blade and taking ibuprofen as needed. Calluses on my feet and pain associated with that I has not changed. I am used to doing it this way so I stick with it. It is by no means a cure, but it helps me keep the condition from getting out of hand. They do not stop or slow the progression of the disease, but they do help keep the calluses from becoming massive They help some but not enough to make a significant difference on a daily basis It works just as well now as it did 10 years ago I occasionally cut my feet and that makes the pain even worse. For the most part, however, they keep the mass of the calluses down I hate the calluses. I would deal with the pain like I have for the past 18 years if my feet could look normal Anything is an improvement, but if everything could be fixed that would be absolutely amazing

Terry K6a Managing my mobility issues.....smart walking, proper shoes, thick socks. Preventive use of antibiotic creams and ointments. Blistering of my feet. Yes, I regularly, in conjunction with my Dermatologist, have labs conducted on my infectious growth to insure that the antibiotics I am using are the most effective. Fairly well, when combined with "smart walking". The treatment goal for me is to eradicate the secondary infection from the blistering. It is a combined effort of meds and "smart walking". Without both, neither does much to improve my condition. Without them, I would be much more limited in my mobility.....so they are absolutely necessary. After years of experience, my current meds and daily walking management are the best for me. Miscalculating my daily walking needs. I get into trouble when I "over walk"usually because I want to do something that I probably should not, e.g., walking a few more city blocks when traveling. A repeatable genetic treatment that would provide freedom from blistering of my feet....even if only for a defined period. Only that we never "concede to this disease", but continue to battle it until it is eradicated.

Tiffany K6b Ibuprofen. Trim calluses, nails. When cysts are ready to drain I drain them. Pain It hasn't changed It helps some, but I'm still in pain daily. I can't imagine how bad my feet would be if I didn't take care of them the way I do. Keeping on top of the calluses prevents them from getting out of control Right now I can still work and live what I consider a normal life. If they keep getting worse like they seem to be doing I'm not sure I can continue working the way I do now. My treatment regimen hasn't changed. Taking the time once a week to soak my feet and then trim the calluses. It takes a long time. And it's annoying to have to try and make it fit in. Decreased pain. Minimize the calluses. Find something that prevents the cysts.

Timothy K16 I see a chropodist every 3 weeks. I am supposed to change my socks to stop my feet getting hot and sweaty. I shave my feet at night and put on cream. I also do streches to improve the way I walk. I do these to try to stop the build up of calluses. my treatment hasn't changed over time although my feet have gotten worse. It doesn't really becuase the calluses and blisters keep coming back. They don't. Not very well. Not very well. I have to miss school to attend the chiropodist. I also am not very good at changing my socks at school because i don't want to miss out or have people ask me what i'm doing. I just want my feet to stop hurting. I haven't found anything that really works although going to the chiropodist helps keep the skin from building up too much.

Todd K16 Weekly maintenance and trimming Worsening pain and fitting of shoes Take a longer due to worsening of condition. It never removes the chronic pain levels None Somewhat improved Very little Time spent vs little reward Pain relegation and maint None

Tom K16 Reduce calluses on feet every 2 weeks using scalpel. I find a certain callus thickness optimum. Too thick and gets more painful, too thin and it's agony! Reduce calluses on feet to reduce pain in walking Not really. Tried creams, drugs for reducing calluses but scalpel has best results. However this has gotten more difficult over years with more blood vessels and less clear differentiation between skin underneath and callus Small pain reduction but minimal gain in reality. Not at all Small amount Small amount Feet hurt even more the day after trimming calluses. Ability to walk more than minimal amount without pain I have thought in the past whether you can just cut off nerves to the feet! I know this isn't realistic but this is how bad it gets. Any treatment to mean could be on feet more with less pain would be incredible to quality of my life and that of my family

Tom K6b use of diabetic insoles to reduce pressure and pain. pain medication to help manage pain trim and cut callouses to relieve pain use of antibiotic ointment on popped blisters to help prevent infection use of wicking socks to help keep feet dry use of "bag balm" to help keep calluoses moist to prevent cracking pain infection seems like when I was younger, my feet were more predictable. they didn't sweat like they do now. also callouse growth has changed in size and growth so new insoles are needed more often doesn't treat the sysptoms of pain much, but it does help a bit. sometimes allows me to walk moe or for longer distances the treament don't slow it enough to talk about. very little just ok.....pain meds

are something I havent used until recently, but it helps to keep me on my feet longer on some days. pain medications can become addictive and cause me to be lethargic. time spent trimming, taping, cutting, cleaning, maintaining feet. cant travel knowing what supplies you may or may not need. if I have a "episode" supplies may not be readily available reducing of callouses and blisters please feel free to contact me with any other questions you may have leftyhitter@sbcglobal.net 209-380-8221 thsank you for the opportunity to participate!!

Vicki K6a I take Meloxicam and/or OTC meds, if needed. anti-inflammatory and/or pain issues It hasn't changed. I am satisfied with my current tx. The treatments do help with the PC. It works okay in daily life. There haven't been any changes recently. No downside. Anything that would decrease the blisters on my feet. No thanks.

Victoria K6a just comfy shoes and soles and Keep nails trimmed and hard skin removed Pain No Hard to answer as grown up with it and always the same pain . Have never not removed the skin to know Don't slow it down just decreases pain for a short amount of time Not much as still have pain and still restrict my walking and standing Ongoing They don't as I do in spare time although chiropodist are expensive and can't afford them and nhs treatment was awful so I never went back so it resulted in me doing it all myself Pain blockers in feet Would love specialist treatment for Pc available on the NHS

Victoria K6b Scrub my tongue, dremel my feet and nails, apply Vicks to my nails and Organica sleep cream to my soles at night Nails and soles, and lack of sleep which causes dementia, inherited From razor blades to dremel Fair at best They don't, but Vicks on the nails seems to suffocate the fungus The rubber sandals allow me to function Chronic dieting helps I sometimes accidentally hit a nerve with the dremel which burns No clue I have small calves due not being able to have a normal gait.

Youmna K16 I spend ime everyday taking care of my feet, I walk as less as possible with special shoes, using a bike for all distances. I used to take everyday pain killers but it secondary effets so I tried limiting them. Pain. As I wrote before I had to reduce taking pain killers who had secondary effects, and where anyway not very effective. It reduces inflammations It does not. Not much. It reduces a bit pain. Not well. I never found a treatment that was very useful. I started having kidney weaknesses with daily pain killers treatment and had to reduce it. I would love to apply a cream that would anesthetize the feeling of pain I have because of my feets. I feel disappointed and surprised to see it takes so long for sciences to find a way to reduce PC pain

Valerie K16 what really relieves and allows to gain a little autonomy is to cut the callositis, but not immediately after. because it feels like just after being machted Pain I need more and more often to cut me my calosities. because I bear less and less the pain they make me live. I am obliged to take anti pains often It's no good It's no stop or slow progression of my disease Nothing For my there Ins't treatments anti

pain gives stomach ache and smear that it relieves the pain, which would allow to walk more and that it limits the growth of the calosity Thank you for all !

Ljiljana not known Mehanicko odstranjivanje noktiju. Odgovarajuće kreme. Talk u carape. Mirovanje po potrebi Nokte. Zuljeve na stopalima Isti je Minimalno Isto je Malo Nisu Nema Zivot bez bola

Kara not known Trim nails using electric nail drill for both hands and feet Removed hard skin and calluses Use creams and body wash ores need to wash with See podiatrist every 6/7 wks Try to find best fitting shoes ,not heavy refrain from very sweaty environments if possible See gp for facial infection? Antibiotics appear to work well for those. Very thick at ti.es psinfull nails on all fingers and toes Hard skin blisters calluses under feet Alot of shooting osind in feet Ecessivly itchy feet that burn at times White layering on tounge Very sore hips from "spikes" trousers rud area also gwt on knees elboes shoulders. Coldsore impetigo very embarrassing when friends keep asking We are still trying to develop the best routine as my sin is only 10 at present but is genetic therefore he can diss use the condition with them if needed All areas treated can be very bad Nothing appears to slow it down ?? Nails get back to immense thickness within 6 weeks Blisters on feet with hard skin are constant, no break from them

Anonymous not known Trimming callouses. Wearing orthotics Painful callouses on feet Not changed Not a lot. Still have pain Do not Helps me walk with less pain Same As I get older find it more difficult to safely trim callouses Stop callous growth and pain relief