Cindy Byers Atha
Executive Director
Pachyonychia Congenita Project

PC Project Appoints New Executive Director
Staff members at PC Project (Mary Schwartz, Frances Smith and Holly Evans) are thrilled to introduce the new Executive Director for PC Project to our IPCC members.

Mary says “I am certain the goal we have all shared over the last years — to develop and deliver effective treatments for PC patients — will move forward and be achieved under Cindy’s leadership.”

Cindy Byers Atha is a Healthcare Executive with a 26-year history of commercial experience in a series of increasingly responsible sales and marketing roles at Atossa Genetics, Depomed, Inc., and Amylin Pharmaceuticals, innovative biotech/biopharmaceutical companies, as well as AstraZeneca, one of the world’s leading pharmaceutical companies. She most recently was the Vice President of Sales and Marketing at Atossa Genetics where she led commercialization efforts for pharmacogenomic testing and medical devices for Breast Health. Previously, she was Vice President of Managed Markets and Trade with Depomed overseeing Managed Care Sales and Marketing, Pricing, Contracting, Trade, and Distribution.

While at Depomed, her team was recognized by Healthcare Distribution Management Association (HDMA) as 2014 DIANA Winner for Best Manufacturer and while performing a similar role at Amylin, her team was twice recognized for “Best Marketing Programs and People” for a small manufacturer and achieved the 2012 DIANA Award for best new product introduction.

Ms. Atha began her pharmaceutical career in field sales with Merck & Co. and then moved to AstraZeneca where she advanced into Senior Sales Leadership. She was the recipient of more than 16 sales awards for exceptional individual and group performance and AstraZeneca’s highly prestigious “Leadership Excellence Award” and "Global Challenge Award."

She helped bring over 16 new pharmaceutical products to market. Early in her career, she was recognized by several key healthcare clients as the best account representative in the industry. She gained formative experience as an Account Executive with Scientific Technologies, promoting the sale of research and medical equipment to leading biotechnology companies and medical centers.

Ms. Atha also serves on the Board of Directors for Operation of Hope, a non-profit organization that provides facial reconstructive surgeries to poor children around the world. She is a member of the Academy of Managed Care Pharmacy and a volunteer mentor for BoomStartup.

She received her Bachelor of Science in Zoology from North Carolina State University in Raleigh, North Carolina. She and her husband William reside in Salt Lake City, UT.

WELCOME CINDY!
**BE A PC ADVOCATE**

We need every PCer and every PC family member to be advocates for PC and PC Project. An advocate is one who supports a cause to help others.

To further help patients and family members be effective in this role, we have developed a training program of several webmeetings and one in-person training session.

Seven individuals in the USA have completed the training and are eager to serve in whatever ways their circumstances permit. Another ten individuals in Europe are now joining the training and will participate at the upcoming Patient Support Meeting and we’ll introduce them in a future NewsBrief.

Our PC Advocate training will continue in the months ahead as we hope to expand awareness, understanding, research and funding for Pachyonychia Congenita through PC Project. The next training will be for PC Advocates in Canada and USA.

We want to be sure that each individual in our PC community thinks “I Am PC Project’ in my own home, on my own street, in my own city, or in my own country. We want to engage and empower everyone with PC to be able to speak up and speak out about PC. We want to help them have the information and tools that will enable them to be effective in this role.

To achieve the goals we have, to find an effective treatment for everyone with PC — we need everyone to do what they can where they are.

Those who are able to have the extra training and be designated “PC Advocates” are here to help as others work to spread PC awareness.

**INTRODUCING PC ADVOCATES AND OUR NEW “CONTACT AN ADVOCATE PROGRAM”**

If you’d like to ask a patient a question or be in touch with a PC Advocate in the USA, please send an email to Advocates@pachyonychia.org

You can address your message to a particular advocate or we will share your email with one or more advocates for you. The advocates will respond directly to you. Please understand, they are patients or family (not medical professionals), they have very busy lives and want to help and support PC Project and all affected by PC. As we introduce this option to connect you, we hope you will understand this is a new effort and help us succeed in this effort and give us feedback.

In the future, we’ll add advocates who are fluent in languages other than English. The Advocates are writing articles for the NewsBrief and we’ll include bio information with those articles.

Juli Bennett (K16)  Christine Block (mother of K6a)  
Albert Bravo (K6b)  Roseann McGrath (K6a)  
Jack Padovano (K16)  Janice Schwartz (K6a)  Stephen Wittmer (K6a)

**NOTE:** One K17 advocate has completed a portion of the training.
UNDERSTANDING PACHYONYCHIA CONGENITA
Frances Smith, Chief Scientific Officer, PC Project

Genotype and Phenotype - very similar sounding words but they mean different things:

Genotype - the genetic makeup of an organism, i.e. the information within your genes. The PC genotype is determined by mutations in any one of 5 keratin genes, KRT6A, KRT6B, KRT6C, KRT16 or KRT17.

Phenotype - is what you see - the physical characteristics of an organism determined by the genetic makeup and environmental influences. In PC, the phenotype - what you see - is thick nails, calluses, blisters, oral leukokeratosis, cysts and follicular hyperkeratosis.

The collection of detailed clinical information together with the genetic testing results from those enrolled in the IPCRR allows us to look for genotype/phenotype correlations within PC. See PC website 'PC Data tab' for summaries of genotype/phenotype observations. There are differences in the PC phenotype depending on the PC genotype. For example, what you see in PC-K6a is different from PC-K17. Oral leukokeratosis is often present in infants with PC-K6a whereas it is rarely present in PC-K17. As the number of individuals within the IPCRR continues to grow, we can narrow things down further and look for correlations between different mutations within the same gene. In PC-K16 we now know there can be a major difference in the nail findings based on the specific mutation with some having few nails affected.

TOPICAL SIROLIMUS UPDATE

Wesley Kaupinen
Palvella Therapeutics

We are pleased and excited to officially announce that topical sirolimus (TD201) for PC patients will be advancing towards its next human clinical study. TransDerm has recently partnered with Palvella Therapeutics, a Philadelphia-based company focused on relentlessly and selflessly serving individuals suffering from rare diseases (Palvella, in Finnish, means “to serve”), to rapidly advance the program. Palvella’s core competencies involve developing and commercializing novel rare disease therapies in the US, Europe, and other geographies. Many of you will have the opportunity to hear more about Palvella and meet their leadership team in the months to come.

Consistent with the goals of any initial study of an experimental therapy in a rare disease, the Phase Ib study of topical sirolimus elucidated several key learning points about the potential for this therapy in PC. The study met its primary objective of demonstrating the safety of topical administration of sirolimus cream for the treatment of painful plantar keratoderma in PC. Topical sirolimus demonstrated an excellent safety profile: there were few local and systemic adverse events, no serious adverse events, and overall the topical sirolimus cream was well tolerated.

The path forward for topical sirolimus in PC will now involve the Palvella and TransDerm teams working closely together to build upon the novel formulation developed at TransDerm and explore the potential to optimize that formulation for the benefit of PC patients. Once that analysis is complete and the FDA has been properly engaged on the status and plans of the program, topical sirolimus will be poised to enter its next clinical study, which will more thoroughly evaluate therapeutic efficacy.

Thanks to all of you for your engagement over many years to advance this promising therapy for PC patients. Success going forward will again necessitate the same extraordinary level of collaboration, and we will again aim to harness the collective wisdom and expertise to design and enroll the next clinical study.
SHOES AND PC

A. Bravo. DPM

Bio: Dr. Bravo (PC-K6b) graduated from Temple University School of Podiatric Medicine. He began private practice in 1986. He is a PC Advocate (see page 2).

Finding the right shoe gear for a PC patient can be a frustrating and challenging endeavor. Due to the foot pain inherent to PC patients, finding the right shoe gear can make a dramatic difference in one’s comfort level. There are many factors to consider in selecting shoes.

The first and foremost factor is to get a proper fit in the shoe. Though quite basic and seemingly obvious, this at times can be overlooked. A shoe that is too tight will place excessive pressure on the foot and lead to early blistering and subsequent pain. However, a shoe that is too loose allows for excessive movement and subsequent friction within the shoe can also prove to be quite uncomfortable. This at times can be difficult to discern, as the tendency seems to be for people to choose shoes with a little “extra” room, however this can be counterproductive. A general rule of thumb is to allow just under a fingers breadth of room between the ends of the toes and the end of the shoe. An easy way to check this is to have someone trace the outline of the foot on a piece of paper when full weight is being placed on the foot, and pull the insole of the shoe out of the shoe and lay this on the tracing of your foot. The outline of your foot should fit the shape of the insole of the shoe. If the toes need to be squeezed together to fit, this will likely cause problems.

The breathability of a shoe can have a profound impact on comfort level. Many shoes are now available with a mesh upper which dramatically improves breathability. Most running shoes and walking shoes can be found with a breathable mesh. Open sandals can provide obvious ventilation benefits, and there are sandals available which have adequate support and cushioning, and which cover the toes, if one would like to have the thickened nails of PC not be visible. Manufacturers such as Keen, Birkenstock, Clarks, etc., and others, have sandals meet this criteria. Certain shoes, such as Clarks, have a ventilation system built into the sole of the shoe which some people find helpful.

Oftentimes PC patients will understandably try to maximize the cushioning within a shoe. However, this needs to be done judiciously. If the entire structure of the shoe is too soft and cushioning, this will lead to excessive movement of the foot within the shoe, subsequent friction, and increased blistering. An appropriate accommodative insole or orthotic placed within a shoe which offers good support and structure, can be quite helpful. Shoes which have a stiff, rocker-bottom sole on the outside, and an appropriate insole on the inside, can be quite helpful in redistributing weightbearing pressure and peak mechanical forces from the symptomatic lesion sites on the foot. As an example, a good quality hiking boot such as Asolo can be quite helpful in this regard. A walking shoe/sneaker called the Swiss MBT shoe can offer similar results. Shoes that are quite flimsy, and twist easily in one’s hand rather than have some structure to them, usually are less than optimal choices for patients with PC, due to the friction will develop within the shoes.

Many people with PC find that certain shoes make the feet too hot, significantly increasing their symptoms. This needs to be judged on individual basis, because certain shoes that may be excellent in other regards, may have an insole to which one is sensitive, making them difficult to wear. As an example, I have had Rockport shoes which can be quite helpful, however the foam lining of the shoe causes a great deal of heat buildup, sensitivity, and discomfort. I remove this and substitute my custom foot orthotics and the problem is solved.

Integral with choosing the proper shoe is selecting the proper socks to wear. All cotton or wool socks are generally best avoided, as they tend to accumulate a great deal of moisture and heat within the shoe. Moisture wicking socks, of which there are many brands (Wigwam, Nike, Darn Tough, ThorLo, etc.), generally can be helpful. Wearing nylon stockings within the shoe likely will exacerbate heat buildup and perspiration, and is often best avoided. Barefoot walking can be helpful in shoes which will absorb perspiration and keep the moisture away from the skin. However can be problematic in other shoes. For people who live in cold climates,
winter boots with thick felt liners, such as Sorel, can be helpful as the felt liner will absorb a considerable amount of moisture. If a prescription for Bilateral Foot Orthotics is needed, it can be used in conjunction with the felt liner.

Once a well fitted shoe is selected, attention can then turn to an appropriate insole. Though individual responses may vary, a properly fitted insole or orthotic can often provide dramatic improvement. There are literally hundreds of types of materials available for insoles and orthotics, and the proper material needs to be tailored to the individual patient. This can be a frustrating search, as initial poor results with an insole or orthotic tend to lead the patient to abandon further endeavors in this regard. Consultation with a professional skilled in the selection of insole and orthotic materials, design, and fabrication can be quite beneficial.

Alternating shoes daily and changing shoes halfway through the day, or even several times a day, can be helpful by reducing repetitive pressure to the same spots on the foot.

There are many shoes which fit the above-mentioned criteria, and some of these are listed below:

Hoka: Running shoe which has a good rocker-bottom insole

Pedor, Drew, Dr. Comfort: Have shoes with added depth to accommodate insoles and orthotics

Asolo, Oboz: Have hiking boots with good support and good rocker sole

Abeo: Have attractive comfort dress shoes which can accommodate an orthotic.

Finn Comfort: Very expensive, however very well made, proportioned to the foot, cushioned, supportive.

Wolky, Birkenstock, Keen, Clarks: Have sandals and shoes with good breathability and support.

One needs to remember that there can be a great deal of variation in how different PC patients respond to the same footwear. However if one keeps in mind basic general guidelines such as adequate fit, ventilation, support, and consideration of various over-the-counter and custom insoles, hopefully some improvement in comfort level can be achieved.

NOTE: We will add these shoe names to the PC Wiki on the website along with other hints from PCers.

FROM THE PC EMAIL BOX

“I had back surgery and they suggest walking several times a day for 20 minute intervals. My feet cannot handle that. They don’t believe me. They say: Feet cannot hurt that bad.” The physical therapist keeps saying the best thing is a lot of walking which I just can’t do. I told the surgeon about PC and asked him to call PC Project. He seemed interested, but never called PC Project. They gave me a prescription for bilateral orthotics. Is there anything PC Project can do to help insurance pay for the cost of the orthotics.”

IN A PERFECT WORLD

Our heart broke when we read this email. We sent a letter of support, but trying to be of help after a surgery is not effective. Here is what we wish had happened and a much better result. Our wish email: “Thank you so much for helping me with my back surgery. Having the dermatologist and pain specialist connect with my surgeon prior to the surgery made all the difference. Also, please tell the physical therapist ‘thank you!’ for the information she shared and for advising a recovery program that worked for someone with PC! Also, I’m glad to report because the medical team understood how important the bilateral orthotics were in this situation, they were able to get the insurance company to agree to partial payment which has really helped.”

QUESTION OF THE MONTH

Have you ever had a prescription for bilateral orthotics? Yes/No
If yes, were they helpful? Please explain
Send to: info@pachyonychia.org

MANY THANKS!

Attached is a marvelous collection of responses from the survey in August NewsBrief from 15 PC patients who took time and shared their experiences. We think it is very valuable information! Enjoy!
In August 2016, PC Project conducted a survey within the PC Patient community asking about employment. As of this printing, 15 patients have responded from six countries including Australia, Belgium, Canada, England, Finland, USA and Wales. The PC community is amazing!

The PC community is so amazing! In this supplement, we have responses from
10 PC-K16
4 PC-K6a
1PC-K6b

They have shared excellent, important, insightful information which we feel will be valuable to all in. Thanks to each PCer who shared to help others!
PC K16 Job Title
Administrator/Public Administration

Describe the work you do. I work 4 days a week in public administration. We have about 700 employees here and I work for the department "facility management". I'm in charge of the customer service. I answer a lot of calls from employees who need something or want to report something (i.e. to fix a light bulb). I report all these questions in the system and give the instruction to the right executor.

Does your work affect your PC? I don't have any problems with PC at this job. I just have to sit on a chair all day. It's a big building but there are elevators everywhere. I only walk to the cafeteria that's in the same building and a maximum 100m to my car on the parking lot.

Recommend for others with PC? Yes. Most people here don't even know that I have a disability. Some days, when it's really bad, they see me walk with difficulty and I just say that I hurt my foot or something.

Suggestions for PC Kids? It took some time for me to make this choice. I never wanted to do this type of job. I first tried to follow my dream to be an actress and singer on stage. I also tried to be an event planner. But after depression and burn out, I decided I've endured enough pain and I gave it all up. Now, I like my job and I'm grateful for it. I'm good at my job. People like me and I don't have to suffer any more. Acting, singing, planning, being creative - it's for my spare time where there's no pressure at all. You have to decide for yourself how much pain you want to offer for a job. Follow your dream and see how far you can go!

PC K16 Job Title
Claims Manager

Describe the work you do. Manage commercial risk, claims, and litigation; analyze trends and mitigation efforts; reconcile associated accounts and loss runs; monthly and quarterly reporting to CFO; assist other departments to ensure compliance (with) laws; develop modified return to work programs; write articles, white papers, and best practices directives; create and assist with employee safety training.

Does your work affect your PC? Wearing high heels to complement business attire can be very harsh on the toes and feet. I have occasionally encountered situations of having to walk more than normal for client meetings, inspection of premises, or travel.

Recommend to others with PC? Yes. Working in an office environment provides the ability to stay off your feet for much of the work day.

Would job counseling from PC Project be helpful? Yes. Especially for those still in school, it would be helpful to become knowledgeable about the various professions one can choose from along with the demands of those professions.

Any additional comments about PC and employment? It would be very nice if scholarships or grants were available for PC patients to increase their ability to choose a career that can accommodate the disability.

PC K16 Job Title
Mom, wife, Pastor, residential counselor for mentally disabled

Describe the work you do? I am up and about a lot. I am on my feet when able. I visit people, clean, basically anything that needs to be done.

Does work affect your PC? The good thing about my job is that I don't have to stand if I can't. My whole life revolves around how much my feet hurt that particular day.

Recommend to others with PC? Yes. You can be flexible in what needs to be done.
Change jobs if you could? No.
Suggestions for PC Kids? Try to choose something that you are not on your feet all the time—a job that you can sit parts of your day.

Would a letter from PC Project to your employer be helpful? No. I am my own boss now and the group home owner helps me and knows sometimes I need to sit down.

Would job counseling be helpful? No. I am able to sit when I need to in all my jobs.

Comment Choose wisely and know there’s a job just right for you.

PC K16 Job Title
Medical secretary

Describe the work you do? Office work and customer service at a hospital, medical transcription, booking appointments, advising patients, checking their contact info, etc.

Does your work affect your PC? Not much. I only walk a little each day.

Recommend to others with PC? Yes. If anywhere, in a hospital your colleagues understand your special needs. Patients are so concerned with their own condition they seldom notice my nails—no one has ever said anything. I would not be able to work as a nurse and would not want to be a doctor, but this way I get to do something to help others with medical problems. I learn something new every day—it's a fascinating world!

Change jobs if you could? No.
Suggestions for PC Kids? Follow your heart but be realistic.

You may not be able to do exactly what you would like, but there may be a way to do something almost like it. Talk to someone who knows the field you are interested in and ask if there is a way to make adjustments so that you can do the work. The world is full of possibilities—find out what they are. Read, ask, listen, be curious—you may find professions you would enjoy you didn't even know exist! This is what happened to me!

PC K16 Job Title
Case Manager Supervisor for the State Assistance Program

Describe the work you do? I worked with a provider for the State Family Aid Services to provide low income families, who were eligible for cash assistance programs, to obtain employment. This included identifying barriers and attempting to provide services to eliminate the barriers (Among many other things).

Does your work affect your PC? Being that I was at a desk, the main problem was always the dress code. The work shoes that was decided for the dress code was strict, but I managed to find some softer options that were acceptable both to me and to my employer with out intervention.

Recommend to others with PC? Yes. This is a computer driven desk job which most people with my disability can function at and succeed. In addition, I found the job very rewarding on many levels.

Change jobs if you could? No.

Suggestions for PC Kids? I never knew what to shoot my star for when I was young because, like most of us with PC, we are very grounded in what we know we can do physically. I got lucky and loved computers back in the early '80's when they were new to the general public, and even got a low end certificate in programing and such back in 1980-ish. Even so, for most of us, with or without a physical challenge, we have to do what we like to do because we work so many hours, we have to find some joy in our job, whatever we choose. What I suggest is to keep trying different things to see what fits your physical and mental abilities. That if there's one thing that you LOVE to do, but can't do full time, just remember that you can still do it, just not as much maybe as you would like. Don't give up, keep pushing yourself to the limits, so you can keep growing. For PC'ers desk jobs rock, but some of us don't have to be limited so much and some of us struggle even with that.

Comment In my lowly opinion all PC'ers should have extensive training in anything computer tech. And I'm not telling anyone anything new when I say, there are plenty of jobs a PC'er can do with education.

PC K16 Job Title
Patent Attorney

Describe the work you do? Desk based, intellectual property advisor, so time mostly spent obtaining IP rights for clients and advising on infringement of third party IP rights.


Does your work affect your PC?
Not much

Recommend your career for others with PC? Yes. Interesting job and no requirement to be on your feet.
Change jobs is you could? No.

What suggestions do you have for our PC Kids (under age 18) about their future job choice? I had no thought about the future and whether I would be able to do certain jobs at 10 or 15 years of age. As it turns out I wouldn’t be able to do jobs that meant I was on my feet. So, do what you want and can when you are young (I was a helibike guide for a year) but when planning a career to the fact that as you get older the condition might well become slowly worse to manage.

PC K16 Job Title
Personal outcomes worker (dsw)

Describe the work you do? I work with individuals with intellectual and physical disabilities.

Does your work affect your PC? It was pretty bad as I had to do a lot of walking but, with the help of my family doctor, I now have an accommodation for night shifts which is so much better.

Recommend your career for others with PC? Yes. It’s a great job. Honestly what job doesn’t hurt our feet?

Change your job If you could. Yes—I’d be the boss of course

What suggestions do you have for our PC Kids (under age 18) about their future job choice? Make the most of your education. Work smart not hard. You have to be happy in whatever you do, so to me it’s an individual decision and what you are willing to sacrifice for PC.

Would a letter from PC Project to your employer be helpful? Yes. It would further help educate them to PC and possibly help understand why I’ve asked for night shifts

Would job counseling from PC Project be helpful? No. I’m here till I retire.

PC K16 Job Title
Air Traffic Controller

Describe the work you do?
Tower and Radar Terminal Controller, control over 1000 flights every day in and around Sydney Airport in Australia.

Does your work affect your PC? It doesn’t really. I get to sit most of the time, but I sometimes stand which doesn’t really worry me.

Recommend your career for others with PC? Yes. Minimal walking - and an amazing career

If you could, would you change your work to something else? Yes. I have plans to work for myself eventually, not because I dislike the job at all...just another path I’m planning on.

Comment If its not a job that involves excessive walking/standing don’t let PC be an issue!

PC K16 Job Title
Medical Laboratory Scientist

Describe the work you do? Collect blood, process and analyze it. Process patient samples. Work with doctors and nurses to assist with patient care.

Does your work affect your PC? Some days I am forced to be on my feet and the hard floor a lot, and it’s very hard. Other days I can sit as much as I wish. There is a lot of walking just to get to and from my car either way. I also think my coworkers don’t like when I sit too much because my feet hurt.

Recommend your career for others with PC? No. I say no, because most of the time you don’t get a choice to sit if you want to, because you need to put the patients needs before yours. There are jobs within the field that are more flexible that I would recommend.

If you could, would you change your work to something else? Yes. I would like to go into IT or something else with more choices.

What suggestions do you have for our PC Kids (under age 18) about their future job choice? I tell my kids all the time, don’t choose a job that forces you to be on your feet. Tell your employer as soon as you can so you can be accommodated if needed. I’ve been at my job for 13 years and am still too afraid to ask for accommodations.

Would a letter from PC Project to your employer be helpful? No. They don’t care enough about their employees.

Would job counseling from PC Project be helpful? Yes. I really could use some help about what to do. It gets harder and harder as I get older it seems.

Comment If there is any way for
the PC project to help PCers transition from jobs or maybe job shadowing for PCers to see if it would work that would be helpful.

PC K16 Job Title
Veterinary surgeon
Describe the work you do
Consulting and surgery for small animals (dogs, cats, rabbits mostly)

Does your work affect your PC? I find it very difficult physically, and it has been getting worse since starting work as a vet. It is often very difficult to get through the day due to the pain and it means I have to try to recover on days off rather than get to truly enjoy them. PC has been a really big factor in my decision to leave clinics and go into research - I will start a PhD in October.

Recommend your career for others with PC? No. It is not possible to make sufficient adjustments to make the job doable without severely compromising your own quality of life due to pain and even worse for livestock or equine vets.

Change jobs if you could? Yes. I am changing (as above).

What suggestions do you have for our PC Kids (under age 18) about their future job choice? Your mind and drive are what people care about. Where you find your passion, you may not know. In the sporting goods industry, there’s a lot of products that could be made better and having constant pain or hardships makes me a better designer because I’m constantly trying to make things more ergonomic or pain free.

PC K6a Job Title
Drug/Alcohol Evaluation Specialist
Describe the work you do?
Interview prosecuted Drunk Drivers

Does your work affect your PC? No, it doesn’t really.

Recommend your career for others with PC? No. I doubt there are many places that have this career available.

If you could, would you change your work to something else? No.

What suggestions do you have for our PC Kids (under age 18) about their future job choice? Get an education so you can have a career not dependent on walking.

PC K6a Job Title
Sales manager
Describe the work you do?
Selling wine to hotels and restaurants.

Does your work affect your PC? It affects me when I have to walk to get to appointments to and from different venues

Recommend your career for others with PC? It affects me when I have to walk to get to appointments to and from different venues
others with PC? No. I have my own company so I can be quite flexible when I visit people, but if it was full time and working for someone, I would struggle
Change jobs if you could? No.
What suggestions do you have for our PC Kids (under age 18) about their future job choice? Choose something off your feet
Would a letter from PC Project to your employer be helpful? No. I own the company.

PC K6a Job Title
Public Relations and Social Media Manager for restaurants
Describe the work you do? I handle public relations and all social media involving all the restaurants -- nine in total.
Does your work affect your PC? Not at all.
Recommend your career for others with PC? Yes. You get to sit a lot and stare at a computer
Change jobs if you could? Yes. I always loved being a reporter. If the right paper made a bid, I would consider it.
What suggestions do you have for our PC Kids (under age 18) about their future job choice? Follow your heart. Find something that sets a fire in your soul and makes you feel you are doing something that means something.
Would job counseling from PC Project be helpful? Yes. For others.
Comment For years I never told my employer about my PC in fear it would set limits in their eyes to what I could do for the company.

PC K6b Job Title
Finish Cellars Foreman (Brewery)
Describe the work you do? I work in a cold room (36°) and I'm walking or on my feet for about six to seven hours of my day. Because of my job I have to wear safety toe shoes and over them I need to wear a rubber over shoe to protect my feet from getting wet.
Does your work affect your PC? I take pain meds on everyday that I work. The first couple days of the week go by ok as long as they are just 8 or 9 hours days. After that the pain kind of gets a little worse with each day of the work week. By the end of the day on Friday I can't wait to get home and get off my feet. Most every night after work I do as much as I can to stay off my feet not only because they hurt but it also help them rest and feel better for the next day. If I push it to hard to long on any given day I will surely pay for it the next day at work.
Recommend your career for others with PC? No. It's a job that requires you to be on your feet for about 80% of your work day. Because of that I take meds for the pain everyday which helps but by no means makes me pain free. A job where you are off your feet for 80% of your day would be a much better choice.
If you could, would you change your work to something else Yes. I would try to find a job I could do without having to take meds and still control the pain.
What suggestions do you have for our PC Kids (under age 18) about their future job choice? When you choose a career make sure that choose one with your PC in mind. When you're younger it seems to be a little easier to deal with the pain but as you get older you will thank yourself (for choosing wisely.)
Would a letter from PC Project to your employer be helpful? Yes. I think it might help them understand why some days at work I'm walking slower or with a bit of a limp or why I may be irritable. I don't tell people I have PC because most don't understand or don't believe me when I tell them how painful it can be.
Would job counseling from PC Project be helpful? Yes. I think it could help people like me but may be even better for the people with the even worse forms of PC
Comment I do wonder as I get older if working everyday with the pain and the meds affects my overall health. If my liver or kidneys start to show signs of damage do to the meds, I wonder if disability a possible next step for me?

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Thank you to these 15 patients who provided many great suggestions. We will work together to implement many of these good ideas. In the future we may conduct this survey again so that you can also participate and share your experience and ideas. PC Project Staff