JERRY SEINFELD SHOW
For Immediate Release

Last night, January 14, was special for PC Project—an event that will benefit all PC patients around the world, as Jerry Seinfeld pledged the proceeds from his show in Salt Lake City to PC Project. These funds will be used for research and patient services.

Using the photos provided by PC patients with “Thank You, Jerry” signs (as well as signs with comments about having PC), we prepared a short thank you card video. You can view the video card at [www.pachyonychia.org/video_presentation.php](http://www.pachyonychia.org/video_presentation.php) on the website.

With the video card, we included handmade scarfs with each family member’s name embroidered. Also, a special Superman Jerry Seinfeld ‘bobblehead’ (see page 3). We wanted to let him know that he is a superhero at PC Project.

Three 8’ banners with the image at the left were on display throughout the lobby. PC Project also had an information table in the lobby and a group of teen volunteers assisted in collecting donations. More details on this event and the significance to PC Project will be available in future newsletters. We are very grateful to a special PCer (an old school friend of Jerry Seinfeld), who made this amazing event possible.

The spectacularly beautiful Grand America Hotel in Salt Lake City donated rooms for Mr. Seinfeld and his staff to help PC Project gain the most benefit from this show. Special thanks to the Grand America Hotel for this major and generous contribution to help PC Project.
NEWS FROM YOUR CHIEF
SCIENTIFIC OFFICER
Frances Smith, PhD

Some of you may be wondering what my new job entails.... the last two PC News Brief’s have reported my travels around the USA to various meetings and to PC Project in Salt Lake City but what am I doing now back in Dundee?

How many of you when searching on the internet for 'PC, thick nails or keratoderma' have been directed to various medical/rare disease websites and found the information about PC is out of date? One of my tasks is to get these sites updated - a number have been done but still more to do. It’s amazing how many there are! If you come across any sites that you feel/think need updating please let us know and I’ll contact the relevant person to get this done. PCer's - you are from all over the world and speak many different languages - there will be many sites that I will not find, or understand as my linguistic skills are bad! But you can help. Having up to date information easily available about the clinical features, the genes involved, genetic testing and caring for PC is so important and will help not only PCers and their families but also the doctors who diagnose and care for those with PC.

In line with this we have several drafts of potential publications that need completing and submitting to scientific/medical journals. One of these is a report of several PC patients from India who joined the IPCC and have had genetic testing. This paper has just been submitted to an Indian Dermatology Journal. It is important for us to publish these cases in a broad range of journals to reach as many doctors as possible, to educate them about PC.

I'm also still involved in the genetic testing of all new cases and discussing these monthly with the expert PC dermatologists at PC Project who perform your consultations so we can learn more about PC.

U.S.A. BUDGET: BIG BOOSTS FOR NIH & FDA
Recently, President Obama signed into law a year-end spending bill that funds the U.S. government through fiscal year 2016.

The National Institutes of Health (NIH) was a huge winner, receiving a boost of $2 billion and the Food and Drug Administration (FDA) was provided an increase of $133 million! The Orphan Product Development Grants Program at FDA will also receive a boost of $2.5 million in 2016. This is a significant achievement for the rare disease advocacy community, which has been fighting for increased funding for both agencies.

NOTE: The NIH has funded PC Project scientific meetings as well as PC research at TransDerm, Inc. Both of our Clinical Trials (siRNA in 2008 and Topical Rapa in 2014) received FDA clinical trial funding to cover a portion of the costs. The funding recently has been limited. This new legislation is important to our continue research efforts.

PC ADVOCATES TRAINING
The first six U.S.A. PC Advocates have held three training meetings. In the future, once we have developed the training materials and tested the PC Advocate approach, we hope to increase PC Advocates to other countries.

PC Advocates will serve to be the spokespersons for PC Project on behalf of all PC patients and on behalf of our scientific research community. As they move forward in training, they will develop the tools needed to carry the message of PC Project in both formal and informal settings.

PC Advocates will invite and enlist others (patients, physicians, researchers, donors) to join the PC community to aid in pursuing the goals of PC Project to benefit all PC patients. They will share the PC Project story, patient stories as well as current research efforts, clinical trial plans, fundraising needs and more. Their voices will be heard in many settings to increase awareness of PC.

PC PEER COACHES
We appreciate each of you who have volunteered to be a PC Coach to provide support to other patients who have questions or just need a friend. We are waiting on results of our grant application to fund the training program for PC Coaches to know when we will be able to begin this program. There are a number of details to complete before this training can begin — but it is definitely one of our goals for 2016. We will be in touch with you as soon as possible.
GRUNETHAL RECEPTION
On Wednesday, June 1, 2016, Grunenthal GmbH (a major world-
wide pharmaceutical company that focuses on pain research), is host-
ing a special reception for patients with rare diseases.

The Reception will be at the Friar's Club in Manhattan, NY beginning around 6:30 pm. Grunenthal will issue invitations to interested PC patients with more details.

We hope at least 10 PC patients will attend. If you would like to receive an invitation, or if you have any questions, please email Mary.Schwartz@pachyonychia.org.

On February 29, 2016 PC Project will join forces with rare disease patients and health care advocates in the U.S. and around the world for Rare Disease Day. Rare Disease Day is an annual awareness day dedicated to elevating public understanding of rare diseases and calling attention to the special challenges faced by patients and the community.

The theme for this year’s Rare Disease Day is ‘Patient Voice’. This theme recognizes the important role that patients play in expressing their needs and having a voice in their own care. This theme was selected to ap-}

We encourage our PC Project friends and family to get involved and use your ‘Patient Voice.’ Let those around you know what it’s like to have a rare disease, or care for someone you love who is impacted by a rare disease.

For information about Rare Disease Day in the U.S., go to www.rarediseaseday.us

For information about activities in other countries, go to www.rarediseaseday.org

Jerry Seinfeld Show—January 14, 2016—Abravanel Hall, Salt Lake City, Utah

Nearly 2,800 excited fans crowded into the theatre to enjoy a hugely successful stand-up-comedy show. At the end of the show, he thanked the audience for supporting the organization (PC Project) in the lobby. We were able to give out thousands of small handouts about Pachyonychia Congenita, a number of people viewed our displays and talked with us about what PC is and how Jerry Seinfeld came to know about us. We appreciate each of you PCers, members of the audience, and friends of PC who sent thank you tweets!
PC PAIN STUDIES

The 2011 Pain Study has now been published and is available on our website in the Published Research Articles. The 2014-2015 study will be published shortly.

We received this very valuable question in our email about PC pain studies — “Regarding the pain study, I assume we needed to ‘prove’ that there is pain associated with PC before we could consider treatments? I am simply curious.”

Here is our response to this great question, which this patient encouraged us to share with all:

1. You and every other patient knows there is pain.
   QUESTION: Have you ever seen a pain specialist? Has there ever been a presentation or publication on PC at any pain association, conference, publication? Do you talk about your pain with physicians? If you say no to these 3 questions, you are quite a normal PCer -- and it is okay. But if we want to solve the PC pain problem, we have to find a way to focus and make others know there is significant pain.

2. In 2004 when we started PC Project, there were about 500 publications on PC cases. Not one mentioned pain. Some mentioned weird things (PC and deafness; PC and mental retardation; PC and...) but not one article mentioned pain.

3. Pain is a very complex area. To get people to focus on pain (not just how thick the callus is), we have to attract research interest from those who know pain. For the first time, in 2011, we had a pain specialist at the PC patient meeting. It was a start. In 2014, we had another respected pain specialist do a more complete study and we had a neurologist/pain specialist speak at the patient meeting. Patients may not have understood the reason, but those specialists got a lot from being there and have spoken to their peers about PC.

4. Apart from that, we now have the attention of one of the largest pharma companies, a firm focused on pain (Grunenthal). They are now looking at PC (a disease they had never heard of until April 2015).

5. So, short answer, YES. We have to demonstrate pain to get traction for research options to focus on pain. PC is a 'skin' disorder (even classified as a 'nail' disorder) and so it is relegated to dermatology -- and dermatologists are great. But dermatologists do not prescribe drugs for pain and do not conduct research on pain. We need some neurologists and other pain specialists to work with dermatologists on PC pain.

These are our first steps into the area of 'PC pain' so well known to PCers and PC pain that is so little known to the medical and research communities.

EMAIL FROM A PC MAMA BEAR

“Recently, my son had an infection in his foot. He gave me the heads up in advance and knowing he would be going out-of-state for a holiday, I wanted to be sure he was OK. I made an appointment with a paediatrician in an office that had late night openings. I printed out some info from the PC project website and took it with me.

Once the doctor came in I told him what the issue was and that it's part of David's Pachyonychia Congenita. I handed him the paperwork. He said, 'OK, let me see the spot.' David takes his sock off and the doctor says, 'Well, I am concerned about the excess callus-es and the toenails.'

Deep breaths....the Mama Bear is about to come out... So I say, 'Yes, that is what this condition is, you know the paperwork I just gave you. The infection is right here, (pointing at my son's foot.) All I need you to do is prescribe the antibiotic for him and some antibi-otic ointment.' He starts to hesitate and I said, 'The infection is right here, it hasn't come to a head yet and can't be drained, unless you hand me a scalpel and I will drain it right now.'

He said 'Seems you've done your homework...what kind of antibiotic did you say you wanted?' (LOL I should mention my son WOULD NOT let me near his foot with a scalpel!) I am so glad we have the PC Project to help not only with educational information but the connection we get to have with knowing we are not alone in this even when we think we are the only ones with it.”

In Memoriam
Thank you for 160 £ donations received in honor of Edith Hunt
2015 BRIEF FINANCIAL SUMMARY

We are very grateful to the many who have donated funds, time and services to PC Project in 2015.

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2015 Income and Expense Report

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*Includes $9,215 from 2015 Giving Tuesday. An additional $15,255 from 2015 Giving Tuesday was received January 2016.

2015 Donation Summary Report

213 total donors (the most in any year)

- 1 donor gave over $10,000 in 2015
- 5 donors gave $4,000 or more in 2015
- 15 Donors gave $1000 or more in 2015
- 14 monthly donors (our sustaining donors!)

Sponsor matching funds were $220,834

Funds paid for PC Research and Clinical Trials by an anonymous donor

- Stanford University | $20,584 |
- University of Dundee | $87,952 |
- PC Project Fellowship | $75,000 |
- UC Davis | $13,300 |

Total | $196,836

Another Type of “Donation”

We continue to collect PC teeth. The National Institute of Health (NIH-USA) study on PC Teeth is on-going. Please let us know if you have a tooth or teeth to donate. We will send you the Consent Form and packaging. The teeth can be

- Baby teeth
- Molars that are pulled
- Teeth extracted for braces or any other teeth from children or adults with PC. Thanks.

PC Project financial information is audit in January each year under GAAP standards by a qualified CPA firm.
PC PROJECT AWARDED GLOBAL GENES GRANT

We are pleased to announce that PC Project was awarded a Global Genes Grant in the amount of $4,800 for costs in training Peer Coaches. The training materials will be completed and the training will begin shortly with travel to the in-person training session scheduled with the Peer Coaches.

For all who have volunteered to serve as a Peer Coach, we will be in touch shortly with further information. At present we are beginning the Peer Coach program in the USA and will extend it to other countries as the program is more fully developed.

SIX PC ADVOCATES CONTINUE TRAINING

Our first six PC Advocates are continuing training to be spokespeople and advocates for PC Project toward the goals to help all PC patients. We have started in the USA and will add additional advocates as the program is finalized.

Current PC Advocates are -
- Julie Bennett
- Christine Block
- Roseann McGrath
- Jack Padovano
- Janice Schwartz
- Stephen Wittmer

Three web training meetings have been held. Training will continue at a session the day before the upcoming IPCC scientific meeting in May 2016.

As our advisors reviewed individual PC stories, they advised that one-by-one, patient stories have a limited impact. These stories may be effective at Patient Meetings and in other specific venues, but to move us forward, PC Advocates must use their personal PC story to carry the more impactful message of the PC community including all PC patients and the difference PC Project is making with the hope that working together we will find a treatment for PC.

We need to raise millions of dollars to fund clinical trials. We need effective messengers. Our PC Advocates will lead the way in carrying the message of PC Project, educating on PC, and the need for support to a wider audience.

If we don’t tell the world how life is with PC and tell what PC Project means to PC patients, we cannot expect the world to support us.

We encourage everyone to develop a 2-1/2 minute “PC Story” that can be adapted to any audience (a) physicians (b) funders (c) patients (d) educators. And to use that personal story effectively to tell the PC Project story. You want to be able to easily and quickly explain -
- What is PC (many types)
- The impact of PC on your life
- The hardest thing about PC
- Managing/coping with PC
- The importance of PC Project and your hope for a cure.
JERRY SEINFELD DONATES $160,000 TO PC PROJECT
The website Look to the Stars has a short article about Jerry donating the proceeds from the Salt Lake show to PC Project. Also a link to our YouTube ‘Thank You’ video. https://jerry-seinfeld-donates-show-proceeds-to-charity

Scholarship Award. PC Staff member, Holly Evans, received a scholarship grant to attend the Nonprofit Academy of Excellence at the University of Utah during February 2016.

Conference Pass. PC Project was awarded a free pass worth nearly $4,000 to the World Conference on Orphan Drugs to be held in Washington, DC on April 21-22, 2016. Roger Kaspar will represent PC Project at this conference.

Conference Passes. Through our membership in the Coalition of Skin Diseases, PC Project has received passes to the American Academy of Dermatology annual meeting which will be held in March in Washington, DC. The discounted cost to attend without a pass is $1,850. Roseann McGrath, PC Advocate, will attend with her husband Mike. Roger Kaspar will also represent PC Project at the AAD meeting. The CSD annual luncheon is held in conjunction with the AAD meeting.

BBB Wise Giving Alliance
“I’m happy to report that the Pachyonychia Congenita Project meets all 20 Standards for Charitable Accountability. Congratulations.” Email from BBB.

RARE DISEASE DAY
FEBRUARY 29, 2016
To lead up to Rare Disease Day, NORD is holding a special countdown on social media. PC Project was lucky enough to be selected as one of 28 NORD member organizations to be highlighted. PC Project will be spotlighted on Wednesday, February 24, 2016 on the NORD Facebook page. We will also have a tweet posted in the Twitter Chat for rare diseases which will be on March 1st.

There are events around the world for Rare Disease Day. If you participate in your community, please let us know. And, please send a photo! And a little bit about what you do.

The statement is true for every country in the world including the USA (a country that is focused on research). If a rare disease has a treatment, physicians have something to offer patients and are glad

RESEARCH STUDY REQUIRES BIOPSY DONATION
Once again PCer, Ted Clark, donated a plantar biopsy for a special study at the University of Michigan. David Hansen, MD, one of our most dedicated specialists, donated his time, skill and clinic services to collecting the biopsy. You can see Ted is a PC Superhero! The numbing injection is always the most painful part. Also, for this biopsy, some special trimming was necessary, but Ted was a champion biopsy donor. We are grateful to all who are willing to participate and give samples when needed for research projects.

THE BURDEN OF RARE
In preparing for the International PC Consortium Annual Meeting, we often ask leading researchers to also invite young investigators who may be interested in a rare, genetic, skin disease. This thoughtful response was a powerful reminder of the challenges of a rare disease with no effective treatment.

“I don't know anybody around who is especially interested in this area. Because my country (Turkey) is not a ‘Research Country’, physicians usually don’t want to engage with diseases (and families) whose treatment has yet been found. I haven’t heard of anyone even from my dermatologist friends.” Volkan Okur MD Columbia University, NY

2386 East Heritage Way, Ste B, Salt Lake City, UT 84109 · www.pachyonychia.org · Phone 877-628-7300 · Email: info@pachyonychia.org
to see them and prescribe for them. When a rare disease has a completely unmet medical need, the burden for these patients is far greater.

Ultra Rare Disease Burden—no effective treatment
- Misdiagnosis
- Misunderstanding
- Misinformation
- Isolation (feeling alone)

Pachyonychia Congenita
- Pain
- Appearance
- Time for care
- No treatment (unmet medical need)

More on Gene Therapy, Editing or Correction
In the December 2015 NewsBrief (page 2) we wrote about this topic. It is important to understand that the gene therapy drugs we are pursuing for PC to stop the mutant gene from acting do not have any effect on offspring. There is a very big ethical debate at present about gene editing. An interesting talk was recently given by Sharon Terry, CEO of Genetic Alliance. Click here to view presentation.

The Research Process
......& why it takes so long to get results—Frances Smith, Chief Scientific Officer

A huge amount of data is collected every time someone registers with the IPCRR. This is continually added to as new PC patients register and as you update your information as your PC changes over time. This is all highly valuable and important to collect even if it is not used immediately. When physicians/scientists come up with a question we already have a good starting point of data.

Sometimes though when a study is being planned, we realise we are missing answers to a few questions that have been raised. This requires an addendum to be designed, sent out and answers collected. This all takes time. For all studies we want to collect data/information from as many of you as possible to make the results more meaningful. Thank you to all of you who have taken the time and completed these for various studies. All this information gets used and it can take some time for studies to be completed and reported back to you.

For some studies we may have an idea. For example, what type of pain do PCers experience? But to investigate and answer it in a way that will lead to PC pain being recognized and treatments being tested, we must validate the information.

We must find experts in the right area who are interested and have time to do such a study. We are lucky to be working with a ‘pain team’ who were able to attend 3 patient support meetings in Paris, Edinburgh and Newark in 2013-2014 to carry out studies to help us understand pain and PC. For these studies they also need to collect data from non PCers to compare with that from PC patients. The findings from these studies are being analysed. We hope the data will be finalized soon and we will be able to report results back to you.

Question: Would a vegan diet help to make PC better for my child.
Answer: Thank you for your recent email. While obviously a healthy diet is important to overall health, we have no data to support that a vegan diet would affect this disorder in any way. There is no direct connection between the keratin mutation and eating meat. However, a healthy diet that you find best for your overall health is, of course, a good choice.

Question: Here is a link about CRISPR. Do you think we are far from the application of this technique?
Answer: CRISPR is only a new tool to aid gene sectioning. We have demonstrated the effectiveness of siRNA which is another tool with a similar ‘interference’ function. Whatever tool is used for creating the drug, delivery to the cells of the skin is still the main obstacle we have not yet solved.

Question: My baby has a nail infection. What can I do?
Answer: We’ve prepared a summary (next page) which include some tips from an experienced PC mom.
Swollen Nails in PC Babies—we call these infections, but most physicians say this is not an infection. Whatever the right term, many babies and children with PC have this problem at times. If you have a relationship with a pediatrician, physician or podiatrist who understands PC, that is always of great value. This is not intended to contradict medical advice in any way. The nail must be ready before the following steps can be taken.

ACTIONS MANY PCers TAKE WHEN THE NAIL IS “RIPE”
From one of our PC patients (a mom with PC who has two boys with PC) may be helpful. This is not medical advice, but experience advice.

“I looked at the picture and the nails look very familiar. Both my boys often got infected nails as little babies and they looked a lot like these nails. The nail on the left looks "ripe" right now. Both nails may be ready to have the pus released. I would be as gentle as possible and try to do one of two things (or both, depending on which thing works best):

1. Use clean (sterile), sharp, large nail clippers and see if I could make a hole in the nail. Probably start on the side, on the end near the tip. Do it when the baby is sleeping if possible. There will be pressure when the nail is first clipped and that can be very painful. So the softer the nail, the better and if baby is asleep, that’s good too.

2. Use a sharp, clean (sterile) razor blade (I like a double-edged razor blade because it bends) and try to nick at the nail to make an opening, again from the side and end of nail nearest the finger tip. If nothing comes out, try near other areas. This may be a better way than the nail clippers.

- Whether a nail clipper or a razor blade is used, go slowly and gently and not too deep at first. The outer nail is "dead" but soon, inside the nail, there will be "live" nerve endings so be careful.

- Before trimming, if the nail doesn't seem soft, soaking it first by putting the baby's hand in warm water (not hot) for a few minutes will help. Also, after the nail is cut into and the pus comes out, soaking the nail again, or even running it under warm water will help.

The nail itself may fall off at some point once the nail starts to heal. Antibiotics may help the healing, but to heal quickly and to relieve the pain as soon as possible, getting the pus out is important and the pain relief will be almost immediate. Based on my experience, there will be pus in the nail, not clear liquid.

Also, baby pain reliever like baby ibuprofen will help as well. If I had to, I would give the baby some of that before trimming the nail. However, the greatest pain relief will come when that nail is gently cut into and the pus is released.”

NOTE: A topical antibiotic cream can be used after releasing fluid/pus (the same as for blister care.) Oral antibiotics may or may not be needed. If there are red streaks it is important to immediately see a physician for antibiotics. Other times nails can be treated and healed without antibiotics. You will learn to be able to know at what stage the problem is and when to see a doctor. If at anytime you are uncertain, see a doctor.
RARE DISEASE DAY 2016
Frances J.D. Smith, PhD, Chief Scientific Officer, PC Project

Rare disease day started as an European event 9 years ago that takes place on the 29th of February (ie. a 'rare day') or when it is not a leap year on the 28th of February to raise awareness of rare diseases. Now it is a world event with more than 80 countries participating.

RARE DISEASE DAY UK 2016
To mark Rare Disease Day, Rare Disease UK hosted Parliamentary Receptions across the UK, at the House of Commons, London, the National Assembly for Wales, the Scottish Parliament and the Parliament Buildings, Belfast.

RECEPTION AT THE SCOTTISH PARLIAMENT
Frances Smith attended the reception which started with refreshments, a short welcome speech from Malcolm Chisholm MSP, followed by a series of short presentations. First, a patient with the rare disorder, progressive supranuclear palsy, and his wife discussed issues including getting a correct diagnosis, living with a rare disorder and the effect on family life. Alistair Kent OBE, the Director of Genetic Alliance UK then spoke about the role of Genetic Alliance - a national alliance of over 180 patient organisations working to improve the lives of patients and families affected by all types of genetic conditions. This was followed by Jamie Hepburn MSP, the Minister for Sport, Health Improvement and Mental Health who announced the funding of £6m investment by the Scottish Government for the Scottish Genomes Partnership, a medical research collaboration between Scottish universities and the National Health Service. Through collaboration with Genomics England this large sequencing project hopes to offer more rapid diagnosis to rare disease patients or a diagnosis to those with an unknown disorder. Genetic diseases will become better understood and new ways to test, manage and treat these diseases will be developed. The final presentation was by Professor Zosia Miedzybrodzka, a clinical geneticist at the University of Aberdeen. She spoke of her hope of a diagnosis, through the Scottish Genomes Partnership, for some of her patients with unknown rare disorders.

Facts about rare diseases
- A disease or disorder is defined as rare in the USA when it affects fewer than 200,000 people
- A disease or disorder is defined as rare in Europe when it affects fewer than 1 in 2,000

There are 239 genetically confirmed PC patients in Europe (countries in the EU). This means that PC affects fewer than 1 in 3.1 million.

PC is ultra rare and so very rare that to achieve our goals, we need to ensure that every patient and every family member joins the IPCRR and is counted.

- There are between 6,000 - 8,000 recognised rare diseases
  Of these, it is estimated 2,000 are rare skin diseases. PC is one of the rarest of the rare skin diseases.
- 80% of rare diseases have genetic origins. Other rare diseases result from infections (bacterial or viral), allergies and environmental causes or are degenerative and proliferative
- 75% of rare diseases affect children
- Rare diseases are disabling: the quality of life of patients is often compromised

Fact: Collectively rare diseases are not rare.

- Approximately 30 million people in the USA are living with a rare disease
- Approximately 30 million in Europe are living with a rare disease
2016 PC AWARENESS

As can be seen from the information Frances Smith shared about rare diseases (page 1), PC is one of the rarest of the many rare diseases. We are small in numbers, but together we can make a difference for PC.

Although June is PC Awareness Month, PC Awareness efforts can happen anytime throughout the year. Pick your date and what you want to do.

Each family can hold an event (large or small) in their own community.

Some examples from past years include:

⇒ Printing and sending brochures to friends and coworkers
⇒ Posting social media messages on Facebook, Twitter, Instagram
⇒ Hosting a dinner for family and friends
⇒ Holding a yard sale, bake sale, bike-a-thon, carnival
⇒ Setting up collection boxes
⇒ or just chatting about PC with a few friends

Here are some tips for planning your fundraising or awareness action for 2016:

1. Choose an activity that you like. Your activity can be large or small but it will be most successful if you choose something that interests you. Remember that you are the ‘heart’ of the PC action in your own community.

2. Include your friends and family in your project or activity. The more people the better. It is really good for your family and friends to be involved in spreading the word about PC. The more they learn and become involved the more effective we can be at spreading the word about PC.

3. You can register your activity with PC Project by sending us an email, photos and other information.

4. Publicity! If you LIKE our PC Project Organization Page, you can then post on that page. You also can click onto the attached PC Event page and post your event there. This link will take you directly to the PC Project Events page for 2016 https://www.facebook.com/events/503550539833327

5. Don’t forget to have fun while you are planning/holding PC Awareness efforts.

2016 PC EVENTS PLANNED!

Talk with your family and friends and plan what you will do in 2016. Several awareness actions/events have already taken place and many are planned. Please help us achieve our goal of at least 100 PC events in 2016!

FIREWALKING EVENT 2016

From Julie Peconi:

Both my husband, Tom and son Timmy 8, have PC (K16) and as Timmy gets older his feet are causing him more and more pain. As a result, to show him our support and to help raise valuable funds and awareness for PC Project, we wanted to do a big event this year! When a good friend suggested
firewalking as a symbolic way of raising money for a condition where it hurts to walk, we thought it was perfect! For those of you who have never heard of it, a fire walk is basically walking barefoot unharmed over hot burning embers and coals. Although the fire is very hot, with a temperature as high as 1200 degrees Fahrenheit, walkers are trained beforehand to walk safely across.

I have hired a company called Planit Firewalking who have been brilliant and have helped me plan the event at each stage. The Firewalk will be held on **Saturday April 23** up at our local Cricket Club in Mumbles, Swansea, Wales.

We hope to have 40 people signed up to walk and will make it a family event, with a flaming bbq serving hot burgers and hot dogs! We have asked each walker to raise a minimum sponsorship of £100 so if we can achieve our target of 40 walkers, even deducting the cost of Planit Firewalking we should be able to raise a good sum of money for PC Project, while raising awareness of PC and the pain it causes.

**UNICORNS 4 PC SET 2K OBSTACLE RACE IN THE UK**

From Debbie Gregory:

My daughter, Ellie (age 11) and her friends are doing a 2k obstacle race, it's similar to an army assault course. They have come up with a team name 'Unicorns 4 PC' and they have a logo.

Her dad Neil, is going to run the adult race the day before with a few of his friends who will all get sponsorship too.

**PC Awareness 2016 Has Begun!**

**2016 PC AWARENESS**

Seven events held or planned...

1. Seinfeld Show in Salt Lake City
2. AAD/CSD meetings / USA
3. Rare Disease Day / Scotland
4. Firewalking / Wales
5. Unicorns 4 PC / UK
6. Brochures to physicians / USA
7. Golf Tournament / USA
8. Unicorns 4 PC / UK
9. PC Awareness 2016 Has Begun!
10. PC Awareness 2016 Has Begun!
11. PC Awareness 2016 Has Begun!
12. PC Awareness 2016 Has Begun!
13. PC Awareness 2016 Has Begun!
14. PC Awareness 2016 Has Begun!
15. PC Awareness 2016 Has Begun!

**GOAL: 100 Events in 2016**

What's the deal with **Jerry Seinfeld** still doing stand-up? Not that there's anything wrong with that. Find out for yourself when the man who helped invent the modern sitcom comes to town. A portion of the proceeds to benefit the Pachyonychia Congenita Project. Abravanel Hall, Jan. 14, 7 pm., arttix.org or 801-355-ARTS

Thanks to Chris Misiano, the first 2016 Pachyonychia Congenita Awareness Event was the Jerry Seinfeld Show.
This month, (in addition to images from your PC Awareness efforts), we are especially asking for images of PC fingers and toes after nail removal. This isn’t a treatment many PCers have experienced and the results are mixed. We expect the article on PC Nail Removal (first begun in 2012) will be published soon. Recognizing that we need to better understand why some nail removal procedures are successful and some not, we will immediately begin to gather new data using an updated IRB-approved questionnaire. More images from those who have had nails removed will be helpful.

PC Advocate Roseann McGrath and her husband, Michael, attended the 74th Annual Meeting of the American Academy of Dermatologists held March 4-8, 2016 in Washington, DC. Roseann wrote “There must be 10,000 attendees” and she is correct. There are a large number of dermatologists. However, there are only a few interested in rare keratin disorders.

Roseann and Mike manned the booth for the Coalition of Skin Diseases (CSD) and she writes “The booth was in a good location, a lot of foot traffic, but unfortunately not a lot, if any (well 4) came by the booth.”

POST: Happy National Rare Diseases Day! I use the word "happy" because it is a joyful word of celebration. We not only celebrate this day and the awareness it can bring (thank you PC Project and NORD) but also those whose lives have been affected by a rare disease and their abilities to still live life with great joy. This is my Alex (K16) one of the happiest and most active little boys you will ever meet. His daycare has nicknamed him "The Galloping Giggler" as PC has not slowed him down nor affected his spirit.

Two of the four who stopped at the booth were PC Project friends: Roger Kaspar, CEO/TransDerm and Manor Aragwala (New Delhi, India). Both are members of the International PC Consortium. The Coalition of Skin Diseases (CSD) also holds a luncheon in conjunction with each annual AAD meeting and Roseann and Mike also attended and participated at the luncheon representing PC Project very effectively.

Rare Disease Family Camp
For the first time ever, the Hole in the Wall Gang Camp will be hosting a special Summer Family Camp for children and families impacted by rare diseases to join together for a weekend of pure fun - free of charge.

PC Project will send application information to families who are participating with us in the IPCRR (PC registry.)

PC News Brief  March 2016 Vol 11, No 3
**PC Awareness Around The World 2016**

**Use Your Patient Voice to Raise Awareness for PC**

*Matt Morgan, PC Staff*

Why is it so important for PCers to initiate awareness events? Well, we are small. And because we are small we have to have big voices. Large organizations succeed with lots and lots of small voices. Because we do not have the numbers that other organizations have we must have loud voices. Every single PC voice is extremely important to raising awareness and raising funds for PC.

We have been talking a lot here at PC Project about the ‘Patient Voice’ and what that means to us. Each of you has a network of friends and family that can reach much further and do more good in your community than PC Project can on our own. You have the ability to network with your friends and family to create awareness. The key word in network is WORK. The work that can be accomplished by working together with your friends and family and community is more important than the netWORTH of the project. Any project that you do, large or small, increases the size and impact of your Patient Voice.

The point of PC Awareness Month is to generate awareness, but PC Awareness is ongoing. It may be as simple as reading one of the published research articles, taking brochures to your child’s school, posting something on social media to tell people about PC Project and the PC website.

The most important place to let your voice be heard is in your own community. No one else in your community will sound the trumpet for PC. Many simple projects that do not generate a lot of money will generate a lot of publicity and awareness. Your network will also reach people who are not responding to traditional methods of fundraising for PC. Your project is about reach. Through your events you will spread the word and encourage others to participate with you. Be vocal about PC and PC Project. Tell your friends, family, neighbors, co-workers, doctors.


Find a project you like and that will be fun to do!

**PC Patient Support Meeting**

*Edinburgh Scotland*

*October 28-30, 2016*

For information on registration and scholarships visit the News & Events page on the PC website OR click here: [pachyonychia.org/news_events.php#PSM](http://pachyonychia.org/news_events.php#PSM)
INTERNATIONAL PC RESEARCH REGISTRY (IPCRR)
Holly Evans, Program Director

The IPCRR is powerful because of you. Participation in the IPCRR leads to more research for PC. This is why we ask all those affected with PC to join the registry and participate with us even if a relative has previously joined. Each person adds to the data and expands the knowledge about PC.

During March 2016 there were 15 new IPCRR participants from Australia, Bulgaria, Israel, United Kingdom and United States (AL, CA, FL, ID, IN, MT, NJ) 0 updated IPCRR forms 7 Genetic testing kits sent out 9 Genetic Testing Reports sent out

After you complete the forms online and have your consultation and genetic testing, here are a few ways you can continue to make your Patient Voice heard in the IPCRR:
1. Respond to emails, surveys & addendums sent only to IPCRR participants
2. Invite and encourage all affected relatives to join the registry at http://registry.pachyonychia.org/s3/IPCRR
3. Regularly update your/your child’s data and add new photos at https://registry.pachyonychia.org/s3/UPDATE
4. Share photos with us of your “normal” PC. We want to also see the bad times like a bad blister, infection or other problem. These help teach about PC.

INCORRECT INFORMATION
There is a massive amount of incorrect information about Pachyonychia Congenita online and in printed materials. Our PC website (www.pachyonychia.org) is a reliable source of correct and up-to-date information on PC.

However, on the PC website, we include all articles published about PC and related disorders. The best articles are highlighted on the ‘Select Lists’ on the right panel. Some keys to help you evaluate information and articles.
1. Is genetic testing information included? If not, the report may not really be about PC! An example is an article on ‘recessive’ PC. All of the information on our website states that PC is a dominant disorder. This is important. After nearly 8 years, genetic testing showed that the patients said to have ‘recessive PC’ actually have a completely different disorder.
2. Does the information contradict information listed on ‘What Is PC?’ on the PC website? Many single case (or single family) articles incorrectly connect things found in that family with PC. For example, although testing is conducted to establish PC, the article says that hair loss or deafness or some other characteristic is associated with PC. You can rely on the PC website information. Or, feel free to send us an email for an answer to PC questions you may have.
3. Another key is to look at the dates of the publications that are cited. Remember, the genes that cause PC were discovered by Smith/McLean about 1995. Before that date, there were many assumptions and guesses as each case was examined. Most of the best publications on PC have come after we had more than 200 patients in the IPCRR (about 2008 or after).

Social media posts may often have inaccurate information. We hope our responses to several recent posts on our PC Facebook page have been helpful and provided correct information.
(a) PC causes loss of teeth. No. This is not shown in the data available for those with genetically confirmed PC. Other similar disorders do cause loss of teeth.
(b) PC is not a disease because it is inherited. We explained that PC can be described as either a disease or a disorder.

Importance of Genetic Testing
Frances J.D. Smith. Chief Scientific Officer, PC Project

There are many rare skin disorders - some, rarer than PC but they may have some similar features. Some-
times determining which clinical features are linked to a disorder and which are co-incidental can be difficult and confusing. For a doctor it is important to gather a detailed clinical history from a patient to guide appropriate genetic testing, to confirm the clinical diagnosis and identify the exact mutation. Why is this important?

1. Inheritance pattern of a disorder - autosomal dominant (one copy of the mutant gene, like PC), or recessive inheritance (two copies of the mutant gene, like desmoplakin, below). The mode of inheritance determines the risk of passing a disorder on to your children.

2. Care of your disorder - can share information/tips with others with the same disorder.

3. For some disorders, monitoring of symptoms that aren't visible is important. For example, in patients with mutations in the desmoplakin gene, skin blistering occurs soon after birth and then nail dystrophy and palmoplantar keratoderma develop that can look similar to PC. However, hair is sparse and tightly curled. Confirming the disorder by genetic testing is extremely important.

Desmoplakin is found in desmosomes - a type of junction that forms tight links between adjacent cells in skin and also in cardiac muscle. Therefore, in addition to skin fragility & sparse tightly curled hair, the heart can also be affected. Regular monitoring of these patients is necessary to detect any cardiac abnormality early.

4. For a specific disorder knowing the genes involved (their function and where they are found), the exact mutations (the type - missense, deletion etc and the number of different mutations), and the inheritance pattern, together with the numbers of patients determines and drives forward specific research for development of future treatments. This is why, for PC, it is important for PC Project to gather this information and for as many affected family members as possible to enrol in the IPCRR.

EXAMPLES from the IPCRR
Do these two unrelated patients have PC or a different disorder that mimics PC?

Patient 1 has thickened nails (nail dystrophy) and mild callus (keratoderma) on their feet. On closer examination eyelashes were noted to be thin and sparse and eyebrows were sparse.

Patient 2 has nail dystrophy, mild keratoderma and some hair loss since childhood.

Neither patient has plantar pain, oral lesions, cysts or follicular hyper keratoses.

Do they have mild PC? Are the sparse eyelashes, eyebrows (patient 1) or hair loss (patient 2) related to the nail dystrophy and keratoderma disorder? Yes! Do they have PC? No!

Screening PC keratin genes revealed no mutations but a mutation was identified for both patients in the gap junction protein, connexin 30. Mutations in connexin 30 cause Clouston syndrome, an autosomal dominant disorder, with nail and skin involvement plus hair changes. Hair loss distinguishes it from PC but this can range from very mild (and easily missed) to total alopecia (baldness.) Treatments for this will likely not be the same as treatments for PC.

PC ADVOCATE REPRESENTS PC PROJECT
PC Advocate Roseann McGrath and her husband, Mike, attended the American Academy of Dermatology (AAD) meeting held March 4-8, 2016 in Washington, DC. Roseann and Mike helped to staff the Coalition of Skin Diseases (CSD) booth and attended the CSD luncheon to represent PC Project. Roseann provided a detailed report and materials from the meeting. Thank you both!

OBSERVATIONAL STUDY: PAIN APP AND ACTIVITY TRACKER
24 individuals (12 PCers with their 12 ‘normal controls’ who match age/gender/location) have completed the first four weeks (Section 1) of this study. The participants are consistently providing their data. The information being gathered is fantastic. We believe this will be a landmark study in establishing the impact of pain for PC patients. The next section of the study will begin in June. If you’d like to join the study send email to info@pachyonychia.org
PARTICIPATION is the way to ensure your Patient Voice makes a difference.
The chart below lists 10 opportunities PC Project has offered to those in the IPCR and the scores for 25 PC patients.

What is your participation score?
2. Become a donor. Even a small amount makes a difference and a small monthly donation is very valuable.
3. Provide a biopsy if asked.
4. Be active on Facebook PC Patient Chat — and help guide others to PC Project services. LIKE and follow Pachyonychia Congenita Project on social media sites.
5. Host a PC Awareness Event (large or small these matter!) See page 1 of this NewsBrief for more on this opportunity and plan your 2016 event now.
6. The PROMIS survey is closed, but may be collected again. When we have a survey be sure you respond. You are a major part of the PC patient population.
7. Addendums and surveys are sent out as we seek to know more about PC (such as nail removal, use of retinoids, and other special interest research).
8. The 2011 and 2014-2015 pain studies are complete. But other studies will be offered in the future. Will you join in?
9. Activity Tracker and Pain App study is on-going now. If you have plantar pain and want to join this study, send an email to info@pachyonychia.org
10. UPDATE your IPCR data. • Adults – every year • 6-18 – twice a year • Under 6 – 4 times a year • Under 1 – every month

Two additional ideas to increase your participation with PC Project:
♦ Visit www.pachyonychia.org website often to read and learn. Please send us your feedback.
♦ Share your story with us either for the website or just anonymously. Explain how PC affects your daily life? What are your best care techniques?

Remember we are here for you! Please contact us if you have a question, problem or need any service from PC Project.

Together we can make a difference for all those with Pachyonychia Congenita.

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We are excited to report on some of the PC Awareness events for 2016. We encourage everyone to do something large or small to raise awareness, raise funds—and have fun!

Firewalking Event Summary
By Julie Peconi (Baker)
On April 23 at the Mumbles Cricket Club in Swansea, Wales, 40 brave people accepted the Firewalk for PC challenge, walking barefoot over hot coals measured at 1200 degrees!! The event was organised by Julie and Tom Baker to raise money for research into PC. Both Tom and their son, Timmy, age 8, have PC-K16.

The team from Planit Firewalking were in charge of all things fire related and provided an opportunity for 40 people to walk across the coals. While Planit Firewalk owner, Errol, trained the Firewalkers out of sight in the marquee, his sons, Jack and Joel, stoked the fire getting it nice and hot!! Halfway through the training, the Firewalkers were able to have a look at the fire and as you can see by the pictures, the fire was very real! After all 40 firewalkers were feeling ‘strong, powerful and magnificent’ Errol brought them back out where one by one, cheered on by the crowd, all walked across the burning embers! The turnout for the event was amazing and several spectators from out of town said that they could really feel the community spirit.
As part of the event, Tom and Julie also organised a barbeque selling burgers and sausages stacked with hot peppers and fresh produce donated by a local farm shop. Friends also made fire themed cakes which sold out. Overall the event has raised in excess of £4000 for the PC Project while also raising publicity for PC!

In fact many people commented on how it was nice to be raising money for a smaller charity. One person said afterwards that ‘I had never hear of PC, to be honest, but when it was explained, I’d walk on anything to help anyone that has to live with this’.

The event was so successful that the Bakers hope to make it an annual event!

**TIPS ON HOSTING AN EVENT**

We asked Julie to share her six tips for success.

**(1) Choose an event:**
We researched companies who put on fire walk events in the UK. After speaking to a couple, we went with Planit Firewalk. The cost for them to host the event was £1200 for a maximum of 40 walkers, with each additional walker charged at £40. We gave each walker a goal to raise £100, which covers the cost of the walk and raises a reasonable amount per person. We didn’t want the total to be too difficult for each walker to raise.

**(2) Choose a venue for the event:**
We approached 3 different venues (a) a local pub (b) a café next to the beach and (c) the local cricket club. All were keen to host the event without charge, both because it is a charity event and also the potential sale of drinks!

We chose the cricket club – it is a great location with lots of space for the walk and spectators and to allow children to run around without fear of them disappearing too far away. They also supply two large barbecues and are extremely relaxed!

**(3) Organise your event:**
Once the date was chosen and booked with the venue and Planit Firewalk, it became real that we needed people to actually walk! This was the daunting bit as 40 people seemed like a large number. The response was terrific however – it really captured the imagination, and the first 30 walkers were signed up with relative ease! Filling the remaining 10 places took a bit of work persuading certain individuals, but in the end 40 places were successfully filled.

**(4) What else can be done to supplement the event:**
As part of the event, we also organised a barbeque selling burgers and sausages stacked with hot peppers and fresh produce donated by a local farm shop. The barbecue was a success. We brought in 150 burgers and 150 sausages. It was an epic 3 hours, with 5 of us manning the barbecue, taking money, unpacking cheese and cutting rolls. We added trimmings of lettuce and tomatoes and hot peppers and hot sauce which was a success. All the burgers were sold and only a few uncooked sausages remained. The barbecue alone raised over £500! There was also a cake stall with homemade donated cakes, pre-packaged sweets in bags selling for 50p, and also a stall selling homemade sangria. Each was a great success.

**(5) Promote your event:**
As the date approached I took to Facebook relatively often to keep the date of the event in people’s minds. We probably had over 300
people attend, with many just coming for the barbecue and to watch. It was surprising the number of people watching who said they would like to do it if we organised a similar event again.

(6) Rate the success (what made it successful):
Planit Firewalk was excellent. The walkers were taken off prior to walking for ‘training’ which was hilarious! It will be remembered by all who were there for years to come. During the walk itself the spectators made it a real party atmosphere, cheering each walker as they walked the 4 or so steps across the coals.

**SIMPLE WAYS TO RAISE FUNDS WITHOUT AN EVENT:**
- Collect coins - have a jar in the house/office & put in those small coins that fill up your purse & pockets.
- Go out for dinner with friends - skip starters or dessert or drinks & donate the cost.
- Recycle scrap metal - find out about your local scrap metal merchants and what they buy. Then check your sheds/yards for old bits of scrap metal/house hold appliances, car batteries etc. Ask your friends/neighbors - many will find things they’ve been meaning to get rid of for ages.
- Recycle phones or ink cartridges. There are companies that pay for these and supply a box to put at your work or other businesses to collect these.
- Other ideas—every effort large or small really does help.

**EVERY AWARENESS EFFORT MAKES A DIFFERENCE**
The van Der Laan family from The Netherlands continues to raise funds in many creative ways. For example, their local market sells ‘banana boxes’ for a 1€ donation to PC Project. This year they sent 60€ from this project! And the market likes to post the certificate PC Project sends to them! Almost everyone has a market near them. What a great idea!

**GLOBAL GENES**
hosted an interesting webinar *Understanding Gene Therapy.* The meeting recording and slides are available at [https://globalgenes.org/understanding-gene-therapy/](https://globalgenes.org/understanding-gene-therapy/)

**WORLD CONGRESS-ORPHAN DRUG DEVELOPMENT**
Matt Morgan, PC Project, and Roger Kaspar, TransDerm, attended this conference held April 20-22 in Washington, DC to gain insights into ways PC Project can continue to press for treatment for Pachyonychia Congenita, an orphan disease.

**BETTER BUSINESS BUREAU BBB**
has given PC Project a top rating confirming PC Project meets all 20 standards for excellence.

**PACHYONYCHIA CONGENITA PROJECT-EUROPE** has been officially recognized as a charity in the UK. More next issue.

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The PC MailBox

**Tooth Donor Awards This Month**
⭐ Allison Block
⭐ Victor Ponce Hernandez
⭐ Lily Ziebell
The NIH research on PC teeth is continuing and initial reports will be published soon. At the recent IPCC meeting, the researcher thanked us for the baby teeth provided and reminded us that adult teeth pulled for orthodontic work or molars pulled are especially important for this research. Many thanks to all who have contributed to this project.

**Ian van der Laan-Kokx and Mom at the Market with Banana Box Certificate and Prince Carnival**

Ian, a PC patient in the Netherlands, horseback riding.
WANTED

We need you! This month we have lots of requests for ways you can participate directly in the research process and help with various research projects.

Please let us hear from you. If you have any questions, please call us at 801-401-6300 or 877-628-7300.

BIOPSIES. We need to collect 2 or 3 biopsies from genetically confirmed PC patients (KRT6, KRT16 or KRT17) for a project to develop PC stem cells for possible future use in gene correction techniques. These biopsies are much easier than the ones we often need from the affected areas on the soles of the feet. These can be from hip, thigh or any part and can be done by your local physician. There has to be special packaging that we will provide. Also, we will pay any costs not covered by insurance. If you are interested, please contact us at info@pachyonychia.org.

PC AND DEEP ITCH. We know that many of you suffer from what we now call ‘deep itch.’ However, as we did not know about this when developing the IPCRR questionnaire and so we have no data on this. It is not well established and some physicians do not think that ‘itch’ is relevant to PC. What do you think? Is ‘deep itch’ a problem for you? Please send your comments to info@pachyonychia.org.

HELP FROM PARENTS. Do you have any good ideas for choices of shoes and socks for children with PC? From a young age when they are just starting to walk? What are your experiences? Please send your suggestions and comments to info@pachyonychia.org.

PC WIKI. We constantly add your tips and suggestions to our PC Wiki. Let us know your ideas and what you find most helpful in caring for your PC.

BLOOD SAMPLES. As most of you know, we use saliva samples for DNA testing. And, we have collected biopsies many times for specific research studies. A new study from researchers in Germany indicates they can conduct some additional research using blood samples. If you have PC and are interested, please email us at info@pachyonychia.org. We will provide the collection kits and pay any lab costs.

A TRIBUTE TO OUR FRIEND

As some of you may know, our dear friend and fellow PCer, Harry Stergar is on hospice. Although his long hair is gone, his smile and spirit and determination are as strong as ever. Harry decided that since he is on a lot of pain killers, he should give samples at this time — and so on April 21, he arranged with his physician for a visit for biopsies. Roger Kaspar kindly travelled from TransDerm to help with the collection, but due to a travel mix-up, Harry and Debbie actually had to go to the appointment twice! Harry has now also arranged to have teeth pulled for research! He has often filled our email with messages of encouragement, with laughter and with great ideas. We love you, Harry!
We appreciate each of you who have ordered PC tee-shirts! We invite you to send the link above to your family and friends and invite them to order as well. We know shipping is expensive outside the USA and will try to do other campaigns in connection with Patient Support Meetings so everyone can have an opportunity to participate. We encourage each of you to host something in your own community for PC Awareness month. In this News Brief we highlight a number of amazing projects by individuals. This is wonderful. Our goal is ‘less patient and more empowered’ and as you hold an event you are empowered to speak about PC and spread awareness around you.
NEW LOGO FOR PC PROJECT
At the recent IPCC scientific meeting, Dr. Ofir Artzi from Tel Aviv, Israel, used this ‘heart in feet’ logo in his presentation. We liked it so much that with his permission we’ve adopted it for our PC Awareness 2016 campaign. Thank you Dr. Artzi (who by the way, is the leading physician for one of the clinical trials now being developed for PC).

ENGLAND—Darling Ellie Gregory, age 11, and her friends formed the Unicorn Team and ran an obstacle course to raise funds for PC. Her Dad also formed a team and entered the race to raise funds. Way to go!

We invite every PC patient/family to do something big or small to become empowered on behalf of your PC condition.

Have Fun! Raise Awareness! Raise Funds for PC!

FRANCE—Mother’s Day Donations for PC Project
In March, Marie Jose Billeau (at left in photo) spoke about PC Project to Julie Hutchison (center in photo). Julie and Marie Jose read together the monthly PC News Brief and read about doing a good deed. But, Marie Jose said, "What can I do?" Julie had a good idea. She sells organic beauty products from London and she donated a lovely little bag of beauty products as a fundraiser for PC. Marie Jose writes “Well, in France, we have Mother's Day on May 29th, so my husband and my children gave “euros” for PC Project and surprised me with this bag of wonderful products. We are very happy that Julie contributed a little to help PC Project and now I will go to the post to send you the check. JE T'EMBRASSE TRES FORT!”
Dear Friends,

Ela Kislal was born with a rare condition known as Pachyonychia Congenita (PC). The disease is caused by a chromosome mutation which affects the production of keratin. PC patients experience thick nails, painful calluses and blisters, cysts, follicular hyperkeratosis, and a white film on the tongue. PC patients experience almost constant pain.

June is PC Awareness month. All money raised will be donated to the Pachyonychia Congenita Project. PC Project was invaluable to our family when Ela first encountered difficulties related to her condition. They provided free genetic testing to diagnose her disorder and they paid for our attendance at a patient support meeting which provided a chance to meet others with the disease, and to share information about how to best manage her condition. In addition, PC Project hosts an annual research symposium to bring together scientists and physicians for developing and delivering effective treatments for PC, and has sponsored more than 18 clinical studies.

Please consider buying a cupcake. All proceeds will go to PC Project. Also, feel free to take a look at the pamphlets and help yourself to the small paper books. Your help is much appreciated!

We did an ice cream social with our bike club for awareness on Tuesday night. It was great and we raised $500. We are doing a second night next Thursday with the mountain bike club. (Additional donations have also been received at PC Project.)

FRANCE
Friends and Family of Beatrice Wannamacher 1973-2014 Yard Sale for PC Awareness

We were especially touched to see this event held in remembrance of our dear friend, Beatrice Wannamacher who died unexpectedly at the young age of 41. Beatrice provided many services to PC Project and to LeCouer au Pied (the PC group in France). This is a wonderful example of never forgetting our loved ones and doing something special to raise funds to help others who suffer as Beatrice did.

Thank you! Merci!
NEWS FROM PC PROJECT
Since the last PC News Brief in May 2016, lots of important things have been accomplished at PC Project and we’ll highlight a few in this Newsletter.

1. IPCRR continues to grow with an average of two new patients registering every week and now over 1660 registered patients. Please remember to update your information—we can provide a link that lets you skip a portion to make the data input even quicker. And if you haven’t ever filled out the forms—please do that. It is important and it is making a difference.

2. PC Advocates were selected and 8 participated in training prior to the IPCC scientific meeting (see comments in this newsletter.) We will add additional PC Advocates both in the USA and in other countries. In the last News Brief we included a ‘check your score’ article. We urge you to participate in every way with PC Project— we want you to be ‘less patient and more empowered!’ The PC Advocates all scored very high (some 100% in participating in every opportunity they have been offered!) They have attended Patient Support Meetings, updated their IPCRR, answered each survey, etc. All PC genes are represented in this group of highly accomplished individuals. We know they will be able to represent all PC patients with a united voice and help us expand our efforts.

3. The 13th Annual International PC Consortium (IPCC) Annual scientific meeting was held in Scottsdale, AZ.

4. Clinical Trials. It takes an enormous team effort to develop proper protocols that will result in effective outcomes and gain approval of the FDA (USA) and other regulatory agencies in each country. Each trial will be focused on specific groups of patients and in specific localities with physicians who are able to conduct the trials. Informal patient experiments will not move us forward to approved treatments with costs covered by medical systems and/or insurers. We understand how eager physicians and patients are to try these things. We hope we can work together in a coordinated manner to be most effective and gain real results. Many things that have been tried have not been found effective enough to take forward. Also, the details of the trials are not always obvious. For example, in topical rapa some of the individual patient trials have used a formulation that delivers no active drug and are, therefore, not resulting in any successful outcome for these patients.

The following trials are currently in design at PC Project. We don’t know if any of these trials will be approved or successful in helping those with PC but these are the best options at this time:

A. BOTOX INJECTIONS
B. TOPICAL RAPAMYCIN
C. NEW RETINOID DRUG
D. TARGETED siRNA

5. Publications. We continue to publish articles about PC. We have many articles now in the leading dermatology journals and now our focus is to also have articles in pain, podiatry and pediatric journals. It sometimes takes 2 or 3 years for a publication to be completed.

The following articles are about to be published:

a. The 2014 Pain and Clinical Exam study.

b. The results of the nail removal survey from 2011.

c. The results of the biopsy project in August 2014 and the follow-up exams in AZ and NY. This will be a major article in PAIN (the leading journal for pain.)

d. A second article in a podiatry journal.

6. We also arrange individual responses to patient questions and needs. Recently a family in Spain had questions. Dr. Ramon Grimalt kindly translated for us to help this family. Each family and patient is important to us at PC Project.

We feel we need to do a better job of letting you know that we are working hard and clearly focused on our mission goals:

**Fighting for a cure**

**Connecting and helping patients**

**Empowering research**

WANTED

Thank you for the amazing, quick responses for blood and biopsy donors. We are arranging matches for various projects (PC-type to the proper study) and will be in contact with each on you in the next months. Thank you again!
IPCC SCOTTSDALE, AZ
MAY 10-11, 2016
Frances Smith
Chief Scientific Officer

Nearly 50 physicians and scientists from around the world gathered on May 10-11, 2016 in Scottsdale, Arizona for the 13th Annual Research Symposium of the International Pachyonychia Congenita Consortium (IPCC). The first day focused on current research including the genetics of PC and other rare skin disorders, studies on different aspects of keratin biology in relation to PC, developments in EB research and therapy and sweating and ways to measure it. Another topic was pain and understanding pain including a presentation reporting the initial results of the pain study carried out at 3 patient support meetings in 2014/15. Histology of the nail and nail removal as a PC treatment were also discussed. On the second day presentations and discussions concentrated on proposed clinical trials and the importance of measuring clinical trial endpoints to evaluate these studies.

PC ADVOCATE TRAINING
A training session was held on May 9, prior to the IPCC meeting with 7 specialists and the 8 PC Advocates who then joined the IPCC meetings the following two days. Here are comments from a few of the PC Advocates.

Christine Block, PC Advocate
I was honored to attend the advocate training and research symposium in Arizona May 9th-11th. As advocates we met for further training to understand all forms of PC and be able to effectively communicate with patients, physicians, and others. This was also a time for us as advocates to come together and form a team to continue working toward a cure for PC. We also attended the research symposium where approximately 25 researchers and physicians from all over the world presented their current studies on PC treatment. The collaboration of these researchers and physicians was impressive. They all are putting in significant time and effort to find a cure for PC.

As a parent of a child born with a spontaneous mutation, K6a, this was also my first opportunity to meet other PC patients and learn from them. It was an emotional time to listen to the pain everyone with PC lives with on a daily basis but it was also empowering. We came together and became friends and a PC family. The advocates are strong, driven and amazing people.

After spending 3 days in these meetings, I left inspired to continue doing my part to help PC project find a cure. My part is to con-
continue raising awareness for PC, do fundraising to help support PC project, support research, and participate and update my daughter’s IPCRR. These are things every PC patient and family can do. If we all continue to work as a team PC project will continue to do great things!

**Roseann McGrath, PC Advocate**  
Mere words cannot appropriately describe the myriad of emotions from the PC Advocates & Peer Coaches Training and IPCC conference in AZ this May. The days spent together with 25+ doctors, researchers, scientists, patients and the PC Project staff were beyond exhilarating and yet emotionally and mentally exhausting.

The 25+ doctors grew to nearly 50 on the last day as more arrived for the SID conference, but yet came to the IPCC meeting. The coordination, collaboration and synergy were beyond mind blowing. This consortium of doctors are coming together from around the world to conduct clinical trials, share data, research, best practices, grants, and not only what is working, but what is not working.

My husband and I have attended over 2 dozen events since 2004. Whether they are PSMs, Grand Rounds, formal or informal PC gatherings, representing PC Project at larger conferences (SID, CSD, AAD, FIRST, etc.) or giving biopsies, each and every event is an amazing experience. To summarize these events over the 12 years, but especially this IPCC, in one word is “hope!” for not only relief, but a cure. I’m excited to hear more about the outcomes.

We, the PC Advocates are blessed, honored and so pleased to advocate for the patients and to educate the physicians, researchers and scientists (to put a face to their “cells”).

One issue, however, that befuddles me is if these doctors, physicians, scientists from around the globe can come together to collaborate and find treatment for our ultra ultra rare orphan disease, why can’t the patients who make up the IPCRR, our patient consortium, find the time to register and be genetically tested (and update the information each year.) This is the way to thank them and do our part to build towards success.

**Jack Padovano, PC Advocate**  
PC Advocate training lesson learned: Being an advocate is about using your voice to make a difference. The PC Advocate training taught me the power of using my voice to self-advocate on behalf of myself and other people with PC. I learned how to speak in factual terms about PC, how to get and evaluate information, find out who will support me in my journey, know my rights and responsibilities, problem solve, listen and learn, reaching out to others when I need help and friendship, and learn about self-determination.

The PC Advocate Program was based on the premise that I have a powerful story to tell about my life with PC and can use it in a way to educate multiple audiences including other PC patients, scientists and doctors, and people who have never heard of PC. I am delighted and honored to be a PC Project Advocate!

**IPCC lesson learned:** It truly takes a village to find a treatment and eventual cure for PC. The village includes PC Advocates, PC patients, the hard-working PC Project team, and a collection of the world’s smartest (and nicest) scientists and doctors across the world. The IPCC is a special club of doctors and scientists working in clinical interested in collaborating efforts to develop and deliver an effective treatment for PC. These folks are truly committed to helping and unlike most organizations like IPCC, these folks leave their egos at the door. They have one goal: to treat and cure PC.

As I sat and listened to each doctor present different aspects of their work with PC and related disorders, I was blown away by the level of intelligence, commitment, and downright hootspa of each person. In between sessions, I was honored to be able to ask questions since most of what they presented went way over my head! No matter, they took the time to connect and made sure I walked away a bit more educated.

**Stephen Wittmer, PC Advocate**  
I want to give my heart-felt appreciation to PC Project for giving me the opportunity to attend the 2016 IPCC in Phoenix. The meeting felt like a family reunion with scientist and physicians happy to see each other again and welcoming new attendees with open arms. Even a high ranking member of the National Institutes of Health was in attendance. What a pleasure it is to be able to spend my free time at breakfast, lunch and dinner discussing my rare disease with them. These are...
individuals who whole-heartedly care about finding a treatment or cure for Pachyonychia Congenita. The best part about it is that PC Project has done a exceptional job of finding the best scientists and physicians in the world to join their team. The advocate training that we received on the first day was a delight. Getting to know the other advocates was wonderful, and I am looking forward to helping other PCers as they struggle with the same problems that I have lived with all of these years. I can only image the fear that a mother would have after having a baby with a spontaneous case of PC. What a comfort it would be to be able to speak with a patient advocate who could tell them that everything is going to be alright and this is not the end of the world. In fact, you will find that your child will be a special blessing that you could never replace.

PC Project is not just about finding a cure or treatment for us, but it is also a valuable tool for helping patients who struggle with this rare disease on a daily basis. Nothing is better than knowing that we are not alone, and thanks to PC Project that is not the case anymore.

FROM THE PC PROJECT EMAIL BOX

SPAIN-Claudia Avella
(mother of a toddler with spontaneous PC-K6a) Hello, We'd like to share how we care for our toddler's nails. Our son is a light sleeper, so it's not possible for us to cut his nails while he is asleep. During the first year, Dad cut his nails while Mum breastfed the baby who used to concentrate only on the breastfeeding, making nail care easier to do. At around the first year of age it became increasingly difficult to do this because baby was no longer distracted by feeding. We changed our strategy and made nail-cutting more frequent so that baby would get more used to it (and we have also gotten more used to it). Since baby has a bath most nights, we integrated cutting or filing one or two nails each night as part of his bedtime routine after his bath. This is also a two-person job. Dad cuts nails while Mum shows baby a short age-appropriate video on her smartphone (2-4 minutes) and controls the other hand/feet, etc. Baby is now more used to nail care than he was before and cooperates much more. I hope this can help others.

California USA-Andrew Gaskill
Response to request for information on shoes for children.
Regarding shoes and socks -- when our son first started walking we had him in Toms shoes. We found them to be more breathable and flexible than the typical sneaker scaled down to child size. He's 5 now and we have him in Plae shoes, for the same reason. If I had known about Plae shoes earlier we would probably have had them earlier, but I don't know how small their sizes go, or if the smaller sizes are as good as the larger sizes. For socks we just always find nice thick socks to cushion and prevent rubbing. We also let him go barefoot as much as he wants, and he likes being barefoot. On one hand I worry it might make the callouses on his heels thicker, but I think there's also a natural exfoliating effect as well. He has always had the thickest callouses on the sides of his big toe, and the most painful blisters between his toes, and going barefoot reduces that irritation, and it keeps feet dry too.

Response from an unidentified PCer to a recent online post suggesting that those with PC should not have children. PC Project does not give direction in regard to this topic and respects each person's decision on this topic. We felt this response was worth sharing:
I'm sorry but I find your comment (suggesting those with PC be sterilized) to be extremely offensive and short sighted. One of the hallmarks of this disease is the feeling of isolation and the inability to feel normal, yet finding someone who loves you and to create a family with that person is one of the best things anyone could do and gives purpose to an otherwise empty life. Yes, there is a possibility of passing on PC but passing on the joy of life outweighs any unknowable variable of life with PC. And to simply "stop breeding" which would somehow eradicate genetic conditions is laughably dumb. My mother had a spontaneous PC mutation, should she have been put down? Should she be doomed to life the rest of her life alone? These things will happen no matter what. And with medical advancement happening faster than ever, what's to say by the time me or any other young person with PC starts a family that there won't be a way fight it better than ever. NOTE: Currently over 40% of the confirmed PC cases in the IPCRR registry are 'spontaneous' and are not inherited.
Grunenthal Patient Day
June 1, 2016
Grunenthal pharmaceuticals is a company based in Germany and dedicated to pain research. They have recently started a focus on rare disorders involving pain. Those attending the Patient Day were top level executives from Germany and from Grunenthal USA as well as staff members involved in day-to-day research and development at the company.

Four rare disorders were asked to present their story at this all-day meeting held at the Omni Hotel in New York City. The groups were:
- Complex regional pain syndrome
- Duschenes Muscual Dystrophy
- Pachonychia Congenita
- Parkinsons

We were very grateful to be invited. I hope every PC patient will at sometime be able to see the presentation given by Janice Schwartz on behalf of all PCers. In 20 minutes she changed lives! At least that is what people told her afterwards. She explained how PC affects her life, the hardest things about PC and how PC patients manage their PC. She did it with humor, short/clear illustrations that demonstrated her pain (without bemoaning her pain!) For example, she had a photo of when she was a camp counsellor and because it was too painful to walk around the craft tables, she just climbed up in the middle of the table and sat that way to help the kids. Her choice of pictures was effective. As she said “I’m telling you my deep, dark secrets and so now we have to be best friends!”

And she explained how those with PC look completely normal and often mask/hide their pain because it is difficult to explain to others. At the end of the day’s sessions (which were from 7am to 5pm), the Grunenthal CSO, Klaus-Dieter Langler, asked that we form small groups for each of the 4 disorders and come up with things that Grunenthal will do to help us.

Here is our list:
1. Publicize Pachyonichia Congenita in the ‘pain world’ so that people know that pain is a major part for those with PC.
2. Develop some type of training to help those with PC be more familiar with pain, how to talk about it, etc.
3. Provide suggestions for our website to add more pain information.
4. Provide suggestions to revise our IPCRR questionnaire to add better pain questions.

In addition to the above, they will have representatives attend our Patient Support Meeting in Edinburgh and help us gather Patient Reported Outcome Measures (what patients want from a clinical trial.)

The PC team at Grunenthal has already been helping us with statistical analysis which we have never had access to previously. The data from the PROMIS questionnaire which many of you completed has now been analyzed. The data from the Pain App and Activity Tracker is now being evaluated. And, their team is helping us with comments and review of our clinical trial protocols.

We are very glad to have this help from this company. Those working with us are among the best people we have ever met. They are careful not to promise to develop or deliver a ‘miracle’ drug for PC. They currently have no product to sell for PC. I believe the will do what they have agreed to do—and this is an enormous help!

Grunenthal Pain Networking Reception
June 1, 2016
Friar’s Club, New York City
Following the day long meeting, a ‘Pain Networking Reception’ was held where physicians and scientists specializing in pain gathered along with the Grunenthal staff, the four groups who presented in the day meeting and others. Six PC patients from NY joined Janice at the reception. Here are comments from several:

Peter Niketes— I had the privilege to attend the US Pain Networking event sponsored by Grunenthal Pharmaceuticals. To be in the presence of so many doctors and scientists solely dedicated in trying to relieve pain gave me and the other PCers hope that a solution will be found. I had the opportunity to speak to Marco Pappagallo (MD) and Mark Field

About Pain—there is excellent information on the Grunenthal website for patients regarding pain—what it is, how to talk about it, etc.
grunenthal.com/grt-web/Grunenthal_Group/Patients/Understanding/en_EN/265300325.jsp
(PhD) who have spent the last 25 years working on pain relief. I asked if PC pain was different from other diseases. He said yes. His explanation is beyond me to relate his answer. All the PCers present at the reception, and those not present, are grateful to Grunenthal USA and Grunenthal GmbH for their devoted work on our behalf.

Fran Sargianis—Attending the Pain Reception offered an enlightening experience. We were able to discuss our PC traits with a medical professional who was interested in learning anything and everything about PC which will help them to create a solution for our pain. Typically visits with medical professionals result in negative feelings as we are told there is no cure or that we can experiment with different meds. This visit provided a positive feeling as we answered their questions of scientific curiosity. We were not known as a specific number on a piece of paper. Hopefully with the face to face approach the scientists were able to gather important information that could help to change our (pain) future.

Mary Howard—The Pain Reception on Wednesday night was a first for us, so I had no idea what to expect. There were many people milling around talking. We got to talk to various doctors and scientists. I was very impressed at how interested everyone seemed to be in PC. They listened to us and asked questions. I left with a feeling that they truly will work hard to try to figure out how to help us with all our problems.

2016 Edinburgh Scotland—PC Patient Support Meeting
October 28-30, 2016
Best Western Edinburgh Capital Hotel
Friday, October 28th - welcome dinner starts at 5:30 pm
Saturday, October 29 - all day presentations, discussions and meals
Sunday, October 30 - half day meeting with the closing luncheon at 12.30 pm
REGISTER FOR MEETING at surveymonkey.com/r/2016PSM
Please register as soon as possible. There is no cost to register. Fees are paid separately.
MEETING FEES Before September 1, 2016: £50 per person 15 years or over
After September 1, 2016, the fee increases to £60 per person 15 years or over
Fees paid on arrival at the meeting increase to £75 per person. Meeting fees are waived for PC patient and one family member attending a PC Patient Support Meeting for the first time and are also waived for all those under 15 years of age. PC Project and our sponsors pay 70% of the meeting costs which include the meeting room and equipment rental fees and food including Friday dinner, Saturday breakfast, lunch and dinner, and Sunday breakfast and lunch as well as meeting break snacks.
REGISTER FOR HOTEL at reservations@edinburghcapitalhotel.co.uk or by phone 0131 5359988. You are not charged until you check in at the hotel. There is no cancellation fee if you cancel 24 hours ahead of arrival. Be sure to register direct with the conference hotel. £80 for two persons per night (double or twin beds) £70 single person per night Those under 15 are charged only £5; those 15 or over are full rate. Please note that you are attending the PC Project/University of Dundee Meeting. If you are not a hotel guest, you will be charged a ‘delegate’ fee to attend the meeting. Do not use online or other booking services to book your hotel room for this meeting.
APPLY FOR SCHOLARSHIP FUNDING at surveymonkey.com/r/PSMScholarship
After you have registered for the meeting and booked your hotel reservations, you can apply for a scholarship as needed to cover meeting fees, travel, hotel costs. Application Deadline is July 1, 2016 and awards will be announced August 1, 2016.

If you need assistance in completing the forms or if you have any questions, please contact info@pachyonychia.org

PACHYONYCHIA CONGENITA—EUROPE
We are very pleased that after nearly six months of preparation and effort, the new Pachyonychia Congenita Project Europe has been recognized as a charity. The entity was founded in Scotland (as a SCIO) and is a part of PC Project. All funds and expense will be a united effort with PC Project.

Officers include Mary Schwartz, Frances Smith (both PC Project staff members) and Phillip Gard (PC Project MSAB and Steering Committee member.) As many of you know, Dr. Gard is a retired physician, a PCer and one who helps us often with the physician consultation calls.

Those who live in countries with Gift Aid (where the government adds a percentage to all donations to recognized charities) can now donate direct to PC Project Europe and apply the gift aid request. We will soon add a page to the PC website to provide direct links and additional information.
New Feature. Starting this month, each issue will feature an article by one or more of the PC Advocates on a topic of interest/importance to those with PC. Readers are invited to add their comments via email or posting on our Patient Chat Facebook Page.¹

¹ Note: The Facebook Patient Chat is for those in the IPCRR. If you haven’t taken time to join the patient registry please do that today — it is the way we are able to move forward.

Back to School
By Christine Block, PC Advocate
mother of 7 year old spontaneous PCer

Summer is flying by and soon we will be starting a new school year. The school supplies are starting to show up in the stores and the kids will find out which teacher they have next year.

There are always worries when kids start a new school year such as will they like their teacher. But when you have a child with PC there are a few more concerns and anxieties.

I have found one of the best ways to deal with my daughter’s PC is to make sure her teacher is aware of her PC right away at the beginning of the year. I started meeting with her teachers when she was in preschool and 4K.

Last year as she started Kindergarten, I contacted her teacher during the first week of school and set up a meeting with her and the gym teacher. We sat down and I explained what PC is and how it affects my daughter. I also took along one of the brochures provided by PC project that explains PC.

The school nurse also has a copy of the PC brochure in her records.

I have found that explaining things early and being proactive can help avoid problems down the road.

I tell the teachers that I don’t want them to limit my daughter or stop her from doing things, but she may have foot pain and need to sit down at times. I ask her teachers to listen to her and believe her if she is complaining of foot pain and explain that my daughter will do anything she can to participate. If she says something is too much she is really in pain. I explained that occasionally she has had nail infections and those are very painful for a few days.

I also encourage her teachers to contact me with any questions or problems so we can trouble shoot together. My daughter has learned that she can trust and talk to her teachers when she is having problems with her PC.

I hope everyone has a great 2016-2017 school year!

Share your comments on this topic. Tell us what things you have found that are effective for back to school.

At what age are kids able to talk to teachers on their own? Age 10? Age 12? Age 15? Or?

Do you have a special experience in helping a child with a difficult experience at school?
PC Awareness 2016 Events
The Buchta family held a local candy drive at their school to help spread some awareness and knowledge about PC.
Great idea!
We appreciate everyone who did something to help others learn about PC and raise funds for support and research.
Thank You!

PC T-Shirt Campaign
PCers, friends and family model their PC T-shirts!
Thanks to all who joined in this PC Awareness effort.
We raised $1,149.41 which will be matched $2-for-$1. This will provide meeting scholarships or genetic tests for patients or additional research funds.
Thank you!
PC Awareness 2016
PC AND PAIN

Although pain is the most basic and widespread concern for patients with PC, over the years PC has been classified as a ‘nail disorder’ and a ‘skin disorder’ with the focus mostly on appearance. Since 2011, PC Project has worked to shift the focus to alleviating the pain patients experience.

We have learned some valuable lessons and will share them with you in the hope that these are helpful points.

1. Those who specialize in pain may be anesthesiologists, neurologists, internists, etc. and may or may not work in a pain clinic.

2. The pain specialist is a somewhat new speciality and there is a wide variety of skill and practice across the pain field.

3. Since the type of pain a PC patient has may be different from other types of pain, you may need to find a specialist willing to learn more about PC. It is different than ‘low back pain’ or other types of chronic pain and the source of PC pain is not yet fully understood.

4. If you want to have help specifically with your pain, the country and community where you live will have a major impact on the services available and who provides those services. For example:
   - In the USA dermatologists do not treat for pain or prescribe for pain. Therefore, patients who are referred to dermatologists may not have an opportunity to receive help with pain from their dermatologist and may need to request a referral to a pain specialist.
   - Non-US dermatologists do prescribe pain medications and treat patients for pain in hospitals and out-patient cases. So, outside the USA, the dermatologist may be the best help for your pain.

Learning to talk about your pain can be valuable. We found a lot of helpful information on pain at the Grunenthal website. There is a link to help you talk with your physician about your pain.

Check it out at; see if it’s helpful: http://www.grunenthal.com/grt-web/Grunenthal_Group/Patients/Understanding/en_EN/265300325.jsp

PC PROJECT MAIL

Where PC is found? — Everywhere! PC is not found more in one country or among one ethnic population than any other. It is found everywhere and is rare everywhere.

- Do you find PC is more prevalent in Scottish or those of Scandinavian or Eastern European descent?
  No. It is the same everywhere and ethnicity is not a factor.

- I was referred to a consultant dermatologist in xxxxxxx as they said I was a rare case as this condition is mainly seen in people of Afro-Caribbean descent and I am Caucasian.
  No. It is the same everywhere and ethnicity is not a factor. The information (even from specialists!) is simply not correct.

- ...it is proven that gluten makes it worse for people with Dermatitis herpetiformis, Eczema, Psoriasis. So I guess it would also make it bad for people with PC don’t you think?

Response from Frances Smith,
Chief Scientific Officer PC Project

“Thank you for sending us these links. As Mary mentioned, psoriasis and eczema are very different disorders from PC. As stated in the links you sent a gluten free diet may help some people with psoriasis/eczema by reducing skin inflammation but probably only in cases where gluten is a problem food and if they have some of the known symptoms of gluten allergy such as digestive issues. It's unlikely to help with PC unless you have a gluten allergy as well and then it might help with any inflammation but not with callus formation or pain.” NOTE: The links imply it is proven helpful, but the actual research articles do not say that.

EXECUTIVE DIRECTOR

PC PROJECT

Mary Schwartz will be retiring and is working with the PC Board on an active search to find the new Executive Director who will lead PC Project forward.

Here is a link to the job posting which includes information on how to apply.

http://jobs.nonprofitjobmarket.org/jobseeker/job/29395705/

Please share with anyone interested. Relocation to Salt Lake City is optional if the applicant has the necessary skills to work remotely.