SERVICES SUMMARY 2013

Patient Services (IPCRR)
* Served 143 new patients who contacted PC Project for the first time
* PC Project now serves over 1,350 patients who either have PC or a similar condition
* Provided 87 physician consultations
* Sponsored genetic testing for more than 60 patients
* 1016 letters sent to patients, local physicians, scientists, editors and others (and over 3000 emails)
* Monthly PC NewsBrief for patients, families and friends
* Maintained PC Facebook and PC Facebook Patient Chat
* Sponsored the 2013 Patient Support Meeting
* Held patient webmeetings
* Send support letters for schools, work, insurance and other for numerous patients

Serving patients 2003 = 3
2013 = 1350

Science and Research (IPCC)
* Sponsored the 10th Annual IPCC Scientific Symposium for PC research
* Sponsored monthly genetics team webmeetings
* Organized quarterly physician webmeetings
* Quarterly IPCC News for professionals working on PC

PC PROJECT FINANCES

INCOME 2013

Donations $ 28,734
Awareness $ 15,443
Golf Tournament $ 7,815
TransDerm Duathlon $ 27,449
Year End $ 30,450
Sub Total $109,894
Wittmer Estate $165,000
Total income 2013 $274,894
$2-for-$1 match 2013 $549,788 for total 2013 income $824,682

EXPENDITURES 2013

Operating Services—$33,090
Misc Office $ 2,787
Fund Raising $ 4,360
Computers $ 4,506
Rent $ 5,400
Admin Services $ 3,152
Professional Services $ 12,885
Program Services—$246,142
Educational Outreach $ 5,196
Videos, Presentations $ 1,600
Clinical Trials $ 23,221
IPCC Consortium $ 37,089
IPCR Registry $ 72,053
Patient Support Mtg $ 39,108
Publications $ 5,735
Scientific Meetings $ 1,247
Webinars $ 415
Website $ 15,688
Genetic Testing $113,291

1 The 2013 tax return will be filed in a few months and posted on our website.
2 NIH Grant additional $27,997
3 Sponsor pays these funds direct to University of Dundee
After eight years of preparation, on Friday, January 17, 2014 the first of 15 PC patients will visit Stanford University for their pre-screening visit for “A prospective, randomized, double-blind, Split-Body, Placebo-controlled evaluation of the safety and efficacy of topical sirolimus (TD101 1%) for plantar keratoderma in adults with Pachyonychia congenita”— the Topical Rapamycin clinical trial! This is an FDA-approved Phase 1b clinical trial sponsored by PC Project in collaboration with our pharma partner, TransDerm, who has developed this topical formulation using the drug product donated by Pfizer.

We thought you would enjoy a brief history of the steps to get to this point. In 2006, Roger Kaspar, TransDerm CEO recognized the scientific basis for using this drug for PC as the drug targets the pathway of the PC keratin genes. A small study was completed using oral rapamycin. Although effective, because of the side-effects, it was clear a topical application was needed and Roger immediately began contacting Pfizer to set up a way to acquire the drug needed for a topical application for PC.

Finally, in 2012, an agreement was reached in which Pfizer committed to donate $500,000 of the drug and TransDerm committed to do the following:

1. Develop a topical formulation for delivery of the rapamycin
2. Obtain ‘Orphan Drug Status’ for the topical drug
3. Complete all the pre-clinical work including animal toxicity studies, chemical studies, etc.
4. Design the protocol for the clinical trial and file with the FDA for permission to conduct the trial.

The topical cream was developed and formulated at TransDerm and Roger and his staff completed all the required animal tests, toxicology tests, chemical analysis and other pre-clinical work necessary.
before a filing with the FDA can be made. This required installation of a ‘clean room’ at TransDerm where the testing was performed.

Orphan drug status is obtained by a special filing to show that the product is for treatment of an orphan drug (less than 200,000 people in the USA). This application was filed by TransDerm and Orphan Drug status was granted for topical rapamycin.

In 2012, TransDeram applied to the FDA for permission to conduct the clinical trial using topical rapamycin and the letter was received in Fall 2012 (about the time of the US government closure.)

All was ready for delivery of the drug from Pfizer. Even the shipment of this drug product across international and state lines under controlled temperature and safety was a feat to behold!

Next, TransDerm manufactured the topical formulation, combined the drug product with the topical formulation and packaged the product into tubes for patient use. This had to be performed under GMP standards for human use again requiring the use of the ‘clean room’ at TransDerm.

Finally, the drug product and placebo product had to be blinded, labelled and all production and procedural checkpoints met along the way. And, instructional materials and videos had to be produced.

We are very grateful to TransDerm staff and the team of consultants working with them (including Lisa Grillone, Ajit Simh and Linda Manza) for their amazing dedication. This is truly an unprecedented accomplishment for a small phama company!

We are also grateful to Dr. Joyce Teng, dermatologist at Stanford University, who is working with TransDerm and PC Project. Dr. Teng and her staff have developed the clinical protocol necessary for an FDA clinical trial and will administer the trial to the patients.
ESTIMATED COSTS
We anticipate that the cost for the Topical Rapamycin Clinical Trial will be well over $1,000,000 (not including the $500,000 drug cost donated by Pfizer).

We are grateful that NIH grants to TransDerm have covered some of these developmental costs. At this time, grant funding in the USA (and elsewhere) is at an all time low and the cost of the actual treatment of patients was not funded. PC Project has pledged to cover those costs which we believe will total about $200,000. As reported in the last newsletter, the $165,000 from the Estate of David Wittmer was a true miracle to allow us to move forward without delay.

PC PROJECT, PC UK AND LE COEUR AU PIED
PC Project is fortunate to have other organizations helping us in our goals. We feature two of the organizations in this newsletter.

Le Coeur au Pied is the PC organization in France, headed by Sylvie Cierpucha. Beatrice Wannamacher has provided invaluable translation services so that PC Project and Le Coeur au Pied can work closely together. One of the most amazing and helpful services of Sylvie and Le Coeur au Pied is to identify PC patients, enroll them in the registry and provide patient liaison in French. Le Coeur au Pied and PC Project have held several patient support meetings in France.

Recently Le Coeur au Pied made a donation of €12,000 (which was matched €2-for-€1 at PC Project) and which will be used to continue services to PC patients in France including genetic testing. We wish every country had a group like Le Coeur au Pied which is so supportive of PC Project’s mission.

PC UK was organized to take advantage of the ‘gift aid’ match. For those working in the UK, the donations to PC UK may qualify for the 28% ‘gift aid’ match.

Donations made to PC UK are used at the University of Dundee (a) in their important research work on keratin disorders, (b) in funding patient support meetings for PC and other similar disorders and (c) for other work that supports our mission. By covering the costs of the Patient Support Meeting, PC UK helps PC Project avoid the costs of ‘exchange’ and greatly benefits our efforts. PC UK also makes donations direct to PC Project (which are then matched).

FUNDRAISING THAT DOESN’T COST YOU ANYTHING!
We need to continue funding PC Project in order to continue our efforts to find effective treatments for all PC patients.

If you shop online, please know that thousands of stores pay a % of your shopping to PC Project if you set up your shopping through our website (and remember to click on your desktop icon when shopping).

Here are three current sites:

<table>
<thead>
<tr>
<th>iGive.com</th>
<th>Listed on the PC Website under Donate/ How You Can Help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shop for Health Goodshop</td>
<td></td>
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</tbody>
</table>

NEW—PC ON AMAZON.COM
Thanks to a tip from a PC family, Pachyonychia Congenita Project is now listed to receive funds from purchases on Amazon.com (US). Here are the details — AmazonSmile is a simple and automatic way for you to support your favorite charitable organization every time you shop, at no cost to you. When you shop at smile.amazon.com, you’ll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to your favorite charitable organization. We hope that is PC Project! (Pachyonychia Congenita Project)

How do I select a charitable organization to support when shopping on AmazonSmile? On your first visit to AmazonSmile, you need to select a charitable organization to receive donations from eligible purchases before you begin shopping.

How do I shop at AmazonSmile? Simply go to smile.amazon.com from the web browser on your computer or mobile device and start your shopping at AmazonSmile.

Can I use my existing Amazon.com account on AmazonSmile? Yes, you use the same account on Amazon.com and AmazonSmile.

How much of my purchase does Amazon donate? The AmazonSmile Foundation will donate 0.5% of the purchase price.

How can I learn more about AmazonSmile? Please see complete AmazonSmile program details. Let us know if your country is listed.
PC Project participated in a special session at the EADV Training Course on Genodermatoses. EADV is the leading dermatology organization in Europe. The six patients represented PC-K6a, PC-K6b, PC-K16 and PC-K17 (four of the five PC types.) Dr. C. David Hansen from the University of Utah gave the formal presentation on PC. Anita Kaier was the patient hostess and arranged an amazing lunch at the top of the mountain and a wonderful carriage ride tour after the training session.

A booklet including IPCRR data and copies of all of the relevant PC publications was provided to each attendee.

If you are interested in hosting an Educational Outreach program at an educational institution near you, please contact PC Project. PC Project recruits the patients, covers the travel costs and provides the printed materials.

We have received excellent reports from those hosting these events, the attendees — and from the patients who participate and no longer feel ‘all alone’ as the only specimen on display, but have an opportunity to meet with other PC patients. By inviting a variety of PC patients, the event is both a more valuable Grand Rounds and also a small patient support meeting.

The IPCRR registry now includes 533 individuals with genetically confirmed PC who have completed the questionnaire. We urge you to be sure all family members join the registry. This is what leads to publications and drives research success!
PC SUPERHEROES

SUPERHEROS have captured our imaginations for decades. Most get their powers in some unlikely way. All SUPERHEROS have these special qualities —

- Selfless
- Integrity
- Courageous
- Responsible
- Accountable
- Humble

Watch for PC NewsBrief SUPERHEROS!

A LOOK AT RECENT EMAILS

We loved this great question —

“I need to register my child online to update the information, but just curious at to how the info I provide online will link up with the IPCRR (registry) data I previously provided in paper format.”

1. All data received on paper forms has been digitized (hand entered) in the IPCRR database.
2. When new or updated information is entered online from the link on our website, the data is automatically saved.
3. It does not overwrite the earlier data and it isn't two different databases or registrations.
4. As we collect more information for an individual at different times, the entries are dated and the age at entry is automatically computed. We can store as many sets of data over time as a person inputs.
5. These individual datasets create a valuable ‘life history’ of PC patients which provide answers to many questions for which no definite answers are now available.

Can you see the value of this as we learn more and more about PC and build quality data that can drive research to find answers for PC? Be a part of creating needed information about PC.

First — every PCer JOIN the IPCC
Next — update by filling in the questionnaire again online on a regular basis.

◆ Every six months for children under 6
◆ Every year for those 6 to 18
◆ Every 1 to 3 years for adults)

So far 21 PCers have updated their IPCRR data by completing the online questionnaire. These are our registry SUPERHEROES!

PCer ESTEBAN ABARCA FEATURED IN COMPANY NEWSLETTER

We were so pleased to receive the CR England Trucking Company Newsletter and see our special friend, Esteban Abaraa featured in “Drivers of The Quarter.”

Another PC SUPERHERO who never quit on his goal to drive a truck!

PC-K6a PARENTS MEETING

In February, we held the first PC-K6a Parents teleconference/webmeeting. About a dozen parents participated — some who have PC and some who only have children with PC. Dr. David Hansen listened in and has encouraged us to continue these meetings.

Because a feature of PC-K6a is leukokeratosis (white film in the mouth and throat) there are some special challenges for PC-K6a babies at birth especially in spontaneous cases. We have noticed that babies who inherit the condition usually thrive without medical intervention. We realize that in spontaneous cases there is no family history and diagnosis often is delayed. These babies often are treated repeatedly for thrush and as the leukokeratosis is so visible (and not recognized as a normal part of PC-K6a), pediatricians are concerned. Frequently an ENT specialist will be involved and seeing the white plaque around the vocal chords (larynx) and the hoarse cry will also be concerned. Because PC genes are wound healing genes, all the looking and checking actually activates and stimulates — and worsens the condition. Another special problem for PC-K6a babies involves issues with sucking which may be related to the ‘first bite syndrome’ (intense pain on first swallow) that PC-K6a children experience.

Our next PC-K6a Parents Meeting will be May 2014. If you would like to join, please contact PC Project.
CLINICAL TRIAL UPDATE
We will comment each month on the status of various treatments and trials to keep you up-to-date.

Topical Sirolimus (Rapamune/Rapamycin)
- FDA Phase 1b (www.clinicaltrials.gov)
- Topical Drug by TransDerm
- Active Drug by Pfizer
- Clinical study Stanford University under direction of Joyce Teng, MD
The best information to read about the active drug itself is at http://en.wikipedia.org/wiki/Sirolimus. The active drug sirolimus does not promote healing. The drug affects the MTOR pathway where the keratin genes are found. If successful, the drug will affect the callus and reduce the associated pain.

Clinical Trial Protocol
- Split body—left foot/right foot treated independently (drug or placebo may vary each foot)
- Placebo controlled—some tubes have placebo and some have drug; the patient will sometimes have one drug tube and one placebo tube and sometimes have both placebo tubes and sometimes have both drug tubes
- Double-blind (after randomization of the tubes, neither the doctor, scientist nor patient knows whether the tube has drug or placebo)

Fifteen patients from six different states are in the formal six month clinical trial. PC Project is paying for the travel and for the administration of the trial at Stanford. The patients have to arrange time off work or school, childcare, etc. to travel eight (8) times to the Stanford clinic in Palo Alto, California over the next six-nine months. In addition, they have to complete a daily survey/diary and complete other tracking forms, have blood drawn for lab test, have photos taken. These patients are PC SUPERHEROES for sure!

Why only 15 patients — that is all the active drug we have ($500,000 value donated by Pfizer)
Why only USA (Stanford) — that is where we have approval for the trial, that is where we have patients able to participate. Our goal is to make this drug available to all PC patients everywhere in the world.

Time Line. The trial at Stanford will continue for six months followed by a three month ‘washout’. Therefore, even if the trial proves both safety of the drug and good effect, we cannot move to the next step at the FDA until about January-February 2015.

1. Our goal is to obtain an NDA (new drug approval) from the US Food and Drug Administration. (a) We will petition the FDA and we will ask everyone’s 100% support to grant the NDA without further testing after this 15-patient trial. (b) If we fail to get the NDA on the basis of this trial and all the other work that has been done on sirolimus, we will be required to spend about an additional year and perhaps $500,000 or more on additional testing.
2. Whether (a) or (b) once we have the NDA, the drug can be manufactured for PCers and available for sale — covered by insurance (or available under special need at no cost).
3. Once the NDA is achieved in the USA, we will extend this to patients outside the USA as quickly as possible in each country.

We need to continue to act as a community with a central, driving goal. Instead of devoting time and funds to the overall goals, one might seek to just help their own family in an ‘off-label’ study. That track will not result in the approval we need to have a drug manufactured and available to all. Shortcuts, or working alone, will not provide success that can be sustained or produce an effective, approved drug that doctors can prescribe. If you have any questions about the pathway we are pursing, please do not hesitate to write — we will try to answer completely and clearly. We value your ideas.

Other Studies
In addition to the topical sirolimus study, other studies are being developed. For example:

1. Botulinum toxin (Botox or Dysport) Injections
We are working with a group of physicians as well as with the manufacturers to develop a clinical protocol and seek support for a formal study. Feet injections are not yet approved in the USA. With necessary anesthesia, the costs are estimated at possibly $100,000 per treatment in the USA.
Once the protocol is finalized, the study will most likely be centered in the UK or Europe inasmuch as the costs are currently covered in those countries.

2. PC Project is initiating a small 10-15 patient clinical study using salicylic acid and urea creams to fully determine and report the effect of these products for PC over a 6 month period and to determine the ‘after’ effects when the products are discontinued.

3. Nail removal data is being analyzed by to see if enough data has been collected. We would like to understand the mixed results and answer the question “Why do nails grow back for most PC patients?”

4. Statins. We are not currently enrolling patients in additional statin studies as the results were mixed and not conclusive as to the effectiveness of this drug for PC.

5. Cyst Study. The initial data has been reviewed from the 12 PC cyst samples collected. We are especially interested in finding more information on PC cysts.

6. “First Bite Syndrome” and PC-K6a ‘failure to thrive’ in infants. Case studies are being evaluated and organized. We need a publication that will help pediatricians diagnose PC earlier and avoid the trauma caused these babies by misdiagnosis.

**PHOTOBOX DEVELOPED BY PC PROJECT**

In order to produce consistent photos of each patient for the clinical trial evaluations, PC Project was asked to develop a special tool.

Shown above is the “Photobox” being used in the clinical trial. It was designed and ‘manufactured’ by PC Project staff (and friends). The camera is mounted on an arm which rotates around the patient’s foot so that the focus and distance are consistent from all views and for each patient. The patient can simply sit in a chair and rest their foot inside the “Photobox.”

**PATIENT SUPPORT MEETING 2014**

The 2014 PC Patient Support Meeting will be held in Edinburgh, Scotland under the direction of PC UK with support from PC-UK and the University of Dundee. We are so grateful for their participation. Both patients and experts are invited to attend. [Click here for DETAILED INFORMATION on the 2014 Edinburgh PSM.]

1. [REGISTER](#) to attend the 2014 PC PSM Edinburgh.

2. [PAY MEETING FEES](#) by donating to PC Project UK or by cheque. £40 for each person over 15 years of age. If funding support is needed, see Scholarship applications below.

3. [BOOK HOTEL ROOM](#) and note PC Project/University of Dundee Meeting special rates. Note: The special meeting rate includes meals and other conference features that are not included on internet special deals. Please book your hotel room with the special attendee meeting rate by telling them you are with the PC Project/University of Dundee Meeting.

4. [Scholarships](#). The meeting fees will be waived for each PCer attending their first Patient Support Meeting (and one family member.) Fees should be paid for additional family members. If you need special funding assistance for travel, hotel accommodations or meeting fees, please first [REGISTER](#) for the meeting and then immediately complete the [PSM Scholarship Application](#). If you cannot complete the forms online, please [connect with us](#) at PC Project.

**PC AWARENESS AND FUNDRAISING**

We have many PC SUPERHEROS who continue to raise awareness, donate funds and raise funds for PC Project research and patient support.

- **Eileen Lusk**—Requested additional brochures to give to medical professionals
- **Claire Gardiner**—Raised funds and secured a match from her employer
- **Harry Stergar**—sends frequent humorous emails to other PCers to keep them encouraged

**7 GiveDirect Monthly Donors**

- 3 Monthly donors by check
- 1 GiveDirect Annual Donor

Thank You!
SUPERHERO  Jim Rittle not only travelled to Salt Lake City and donated two biopsies for some new PC research, he came to the PC Project office and helped to pack his own samples in dry ice for shipping!

ROGER KASPAR, CEO OF TRANSDERM
Roger was also in Salt Lake City to help collect the biopsies at Dr. C. David Hansen’s office and then to ship the new biopsies to scientists for PC research.

ABOUT BIOPSIES
We are very careful when asking for volunteers to donate biopsies from affected areas of PC skin. If you are willing to donate samples, please let us know.

For cysts, we are especially interested in PC-K17 samples (usually when a cyst needs to be removed).

For cell lines, the biopsy is taken from an unaffected area (like a hip or buttocks).

For special research, the biopsy is usually taken from affected and unaffected PC plantar skin.
WE NEED STORIES AND PHOTOS FOR THE PC WEBSITE

Our website is our gateway to the world — to all who are looking for information about PC. We are so appreciative of those who have their stories and photos posted — but we need many, many more. We love all the stories — and the stories really make a difference as people visit the website.

We’d like to change the images on the front page about every quarter. However, we have no other PCers that have given permission to use photos in that way — and we need to prepare the front page photos with a white background, etc. in order to use them.

Please consider sharing your story either in the story section — or as one of the ‘front page’ features. If you’d like help writing your story, just let us know.

THANK YOU PC COMMUNITY

Because we have a website and can accept donations online, we are required to file and pay fees in every state. In some states, we also must have a ‘registered agent’ who lives in that state. We were able to save hundreds of dollars in costs through the willingness of PC families in seven states who have agreed to act as ’registered agents’ for PC Project in their states so we don’t have to pay a company to receive any notices for us. Thank you PC Super Heroes!

IPCRR CONTINUES TO GROW

Welcome new PCers and thanks to those who are updating (re-entering) their information in the registry.

- Every six months for children under 6
- Every year for those 6 to 18
- Every 1 to 3 years for adults

UPCOMING PC WEB MEETINGS

The next two web meetings will be:

**PC-K6a Parents**—Friday, May 16, at 5:30 pm MST. [We may need to hold a second one for those in the UK.]

**PC-K17 PCers**—Friday, March 21 at 5:30pm MST.

If you would like a special web meeting for a PC group, please contact us at info@pachyonychia.org

PATIENT SUPPORT MEETING—OCT 2014

Please register as soon as possible so we can make the best plans. Information at www.pachyonychia.org and News & Events tab. Scholarships are available.

We thought you would enjoy seeing this photo from that first UK meeting 10 years ago.

How many can you name? Please help us identify as many as possible from 2004.
ACTIVE ADVOCACY FOR PC
We wish each of you could share a day with us at PC Project. So many different things happen here every single day. Each month, we’ll try to give you a ‘behind the scenes’ view of our advocacy efforts. This month we will tell you about PC Project’s interactions with other advocacy groups. The disease Pachyonychia Congenita (PC) is a —
(1) skin disease
(2) rare disorder
(3) genetic condition.
There are umbrella organizations for each of these categories and PC Project participates in these groups.

Coalition of Skin Diseases (CSD)

www.coalitionofskindiseases.org

There are 15 member organizations of various sizes. — One of the smallest member groups is PC Project with fewer than 10,000 patients in the world and a budget of $469,000 in 2012.
— One of the largest member groups is National Psoriasis Foundation (NPF) with 135 million patients worldwide and revenue of $7.5 million in 2012. The goal of PC Project is to deliver the same service and success to PC patients that larger groups achieve. The numbers are a clear statement of how much is being achieved for PC — with so few patients and such limited resources. The progress for PC in research, outreach and patient services is amazing.

National Organization for Rare Disorders (NORD)

www.rarediseases.org

NORD’s website states, “There are approximately 6,800 such diseases, according to the National Institutes of Health (NIH). While each disease is rare, when considered together they affect nearly 30 million Americans or almost 1 in 10 people.” PC Project is listed in the section “Find a Patient Advocacy Group.” NORD works mainly on major, high level issues including legislative issues. Recently PC Project joined in NORD’s letter to the US Congress to oppose changes in the USA Orphan Drug Law which would eliminate incentives to make drugs for rare diseases.

Genetic Alliance

www.geneticalliance.org

This organization provides many major resources to assist advocacy for all genetic diseases (not just rare and not just skin). PC Project has just submitted a proposal for a small Impact Awards grant for funds to expand our IPCRR registry services.

Genetic Alliance Community Blog. One of the resources of Genetic Alliance is a blog where patient advocates can ask questions of their peers and receive suggestions and guidance. Recently we noticed two specific problems and were grateful that PC Project is not facing these issues.

I. Problems with access to ‘patient chat’ features.
A recent blog related problems and sad stories of several groups who did not monitor and restrict patient chat to actual patients. We have solved this problem at PC Project by providing two separate ‘pages’ on Facebook.
1. The first is our public Facebook space where anyone can post. Julie Peconi, the wife and mom of PCers, is a volunteer who monitors and posts on this Facebook page. While we realize the PCers can usually detect a scam or misleading information, we remove posts that claim to cure PC by diet, meditation, secret methods that require a fee, or other comments that are not validated.
2. The second PC Facebook space is our PC Patient Chat which is strictly limited to those who have joined the IPCRR registry and have confirmed PC or those who are close family members of PCers. On PC Patient Chat, patients can share their own
experiences, list their specific PC type (i.e. PC-K6a, PC-K6b, PC-K6c, PC-K16 or PC-K17) and know they are sharing comments with others who have a condition similar to their own.

We often receive requests to join the PC Patient Chat from those who are not participating in the IPCRR and who may or may not have PC. We evaluate each contact and invite each person who contacts us to become a part of the registry. That seems to be a very good ‘screening’ test of whether a person really is a patient seeking help. Also, all comments on the public or patient chat sections are reviewed and, if needed, referred to our medical advisors. New information from postings is added to the PC Wiki.

II. Problems with splinters. This isn’t the type of ‘splinter’ that you get in your finger, but small groups of individuals who do not support the main organization and create informal sub-groups with a specific focus. PC is so rare that if we do not act together, we will have nothing but ‘splinters’ and no real progress.

Thank you to PC heroes—LeCoeur au Pied in France and PC UK at the University of Dundee are groups that have formed not to ‘splinter’ but to support PC Project. Both of these groups have their own website and do fundraising to help the main cause of research. We are always open for suggestions, are eager to improve and want to ensure that everyone feels part of the PC community. We are so grateful to the PC community for acting as one unit.

We hope that other local PC groups may organize to provide specific help in language or contact that PC Project cannot offer. And, we hope that all of us will continue to act together in planning research, in providing information, in planning meetings, in publishing articles with accurate and up-to-date data and in working towards a common goal of ‘finding a cure!’

CLINICAL TRIAL UPDATE

We will comment each month on the status of various studies and trials to keep you up-to-date. We trust you with this information and hope that by sharing we will continue to build a strong, unified PC community that can act as one to benefit all.

Topical Sirolimus (Rapamune/Rapamycin)

We are grateful to the fifteen PC patients who are enrolled in the FDA Phase 1b clinical trial being conducted at Stanford University. All are compliant; none have dropped out. This is challenging because it does require daily applications, daily entry into a measurement diary — and, of course, the eight trips to the Stanford clinic. We are cheering for you! Please finish the trial! It is too early as yet to know the results — and with the placebo/drug combinations you will likely not know results until the end of the trial. All of the nearly 600 PC patients around the world are watching and saying ‘thank you!’ to our fifteen clinical trial participants!

Administrative costs have run higher than expected and we have been asked to provide an additional $40,000 to cover these additional costs. We were able to find a donor to help with this — but want to share this so you understand the challenges and costs we face. This wasn’t the $160,000 already committed — or the costs already spent by TransDerm. These are new, unexpected administrative costs as the staff at Stanford handles the processes required for this clinical trial.

Several PC families have shared information on the clinical trial with their local physicians. We are so grateful to those families and physicians who have understood the importance of waiting for the results of the formal clinical trial. Each PCer should feel represented in the trial by the 15 participants. If you have questions, please let us know.

Presentations on the completed two-patient off label study and on the current clinical trial will be given on May 6th at the Int’l PC Consortium Annual Symposium in Albuquerque, NM just prior to the annual Society of Investigative Dermatology annual conference. Your dermatologist is welcome to attend. Please have him/her contact us at info@pachyonychia.org so the IPCC meeting fee can be waived.
**Boutinum toxin (Botox of Dysport) Injections**

We continue to move forward toward a possible clinical trial in Europe for this method. There are many reasons we think the EU may be the better place to hold this trial. It took five years to get to the actual clinical trial for the topical rapa. We have been working on the boutinum toxin for many years. We hope we can move this forward and are working on this every day.

**“First Bite” Syndrome**

PC-K6a — if you or your child have experienced this intense pain on first bite/first swallow, please contact us at: info@pachyonychia.org. We need to gather more detailed information and engage ENTs and other surgical specialists to help us find solutions to this condition. The information patients provide is the fuel that fires the progress. Please let us hear from you.

**Dissolvable Microneedles**

Many of you tested these out at the 2013 Patient Support Meeting in Santa Cruz and have asked about progress. A second testing over a period of several weeks was completed last summer. We continue to test and develop this delivery option and believe it has good promise.

**New Study—PC Plantar Images**

Thanks to Dr. Albert Bravo, a podiatrist and PC patient who will test out a new device with the inventors to measure whether the images have application for PC in measuring improvement, predicting problems, etc. When we have these opportunities, we so grateful that patients always step up and help us out — even with very busy schedules. Thank you.

**Other Studies**

We mentioned several other studies in the February 2014 PC NewsBrief. Thank you for the feedback you have sent. It is helpful and we note every comment. It helps us choose what we are going to focus on next and what your interests are.

**IN OUR MAILBOX**

We are always glad to receive your questions and comments. We’ve noticed that many of the things that we discuss with you via email are topics that are available on the PC Website under the PC Wiki. For example, recent questions have included

- ‘What about tattoos and PC?’
- ‘When was the Philadelphia PSM held?’
- ‘Is PGD available for PC’
- ‘What insoles did BYU find were best?’

We felt a guide to quickly finding info on the website may be interesting and helpful to everyone.

At the top of every page there is a search box. This uses a Google search tool to find information that is available anywhere on the PC website including on the PC Wiki.

Let’s see how we can answer the 4 questions using website search tools.

‘What about tattoos and PC?’ Type tattoo in the box. A new screen will open with links to a statement by Dr. Sancy Leachman which is in the PC Wiki. The same information is also in PC Care and in the FAQ section on the website.

Click on the links to read the info.
We’ll show you several tools to use to answer the question When was the Philadelphia PSM held? First, we typed Philadelphia in the search box ...and in a few seconds had links to information on anything connected with Philadelphia. We then chose the listing for the 2011 PSM, clicked on the link and found all of the details on that meeting.

For the question Is PGD available for PC?, we again used the Google search box at the top of the page. The same search box is also available at the bottom of every page as well. You just need to use one or the other as both searches will give the same results.

PC Wiki—If you have questions about products, care tips or a new cream from your doctor, check the PC Wiki for details. We continue to update and add new information to the Wiki, so please continue to send us your favorite tips, tools, treatments or techniques. We find the easiest access to Wiki information is the Google search box we are demonstrating — but there are also search features within the PC Wiki and we’ll feature those in a future PC NewsBrief.

For the question What insoles did BYU find were best?, we found good results with either the word insole or the word BYU. The insole information was in a PC NewsBrief and also is on the PC Wiki.

On the PC Wiki there are many types of insoles reported by patients and at the top of the insole listing is information on the Vasyli Armstrong II Insole that the BYU researchers found to be most effective for PC. The PC Wiki has links to distributors in the USA, UK, Australia, Canada and other countries.

HELP US IMPROVE—Be a PC Super Hero by giving us feedback on whether these samples are helpful. Let us know how what information you need and how we can help you. We love to hear from you and your input is really important.
Estate of David Wittmer Provides Additional Funds for PC Research

A second distribution has been received from the Estate of David Wittmer. His choice to use Estate Planning choices for PC will make a real and substantial difference for our PC research. We are so grateful. These funds PC Project will continue their mission of ‘Fighting for a Cure, Connecting & Helping Patients and Empowering Research’ to benefit those with Pachyonychia Congenita. We know that when we succeed many others will also benefit from the research discoveries made.

Update on Trial

We appreciate so much the 15 PC patients who continue to be fully compliant in the clinical trial using topical sirolimus that is being conducted for us at Stanford University. This is not an easy task. The trial will be completed late in the Fall (October to December).

In Our MailBox

From a PC-K6a patient “Yesterday I went to a nail doctor. My dermatologist had set it up for me. My dermatologist and both of the nail doctors were thinking I should have my nail or nails removed and said it would depend on my mutation. The nail doctors said it is something with the nail beds or the matrix and different mutations grow or don’t grow back. [NOTE: this is not validated by information in the IPCRR data.]

I don’t know if I would want to have them removed. I told the two nail doctors that my nails for the most part my nails aren’t a problem. They look worst than they feel. I am glad (PC Project) is not asking me to have my nails removed. I’d hate to say no to you.”

We’d love to hear your feedback.

Seeking New Director

PC Project is currently interviewing candidates to join the PC team now and lead PC Project forward when Mary retires. This will allow for a careful transition to ensure PC Project continues successfully in the future. If interested, please contact Jill Perelsen at The Diestel Group at 801-365-0400 or email at Jill@Diestel.com

Vote Today

2015 Patient Meeting

Is it in Indianapolis, Philadelphia, Chicago or New York/New Jersey? Which city do you prefer for the next meeting? Vote by email to PSM2015@pachyonychia.org and tell us which of these you prefer and the month you’d prefer—your vote will make a difference.

Facebook Patient Chat

W provide this service to help patients ‘connect’ with others who have PC. It is a perk for those who join the IPCRR patient registry. Page 4 of this Newsletter many other conditions that are so similar to PC they are confused by experienced physicians. This is important because although these disorders may ‘look alike’ they definitely do not ‘act alike’ and techniques and treatments are very different.

When those who have not joined the IPCRR patient registry ask to join PC Patient Chat, we invite them to first participate in the patient registry — and explain that PC Facebook Chat is strictly limited to those who have joined the registry and actually have PC or have close family member with PC. That has been a very good ‘screening’ test of whether someone is really a PCer seeking help or just ‘curious’ or ‘phishing’ or worse — hoping to make a profit from those with a rare disease.

A recent blog among rare disease patient advocacy groups related many sad stories of groups who do not monitor and restrict patient chat to actual patients. If a person is unwilling to join the PC registry and help in our goals, we do not open the Facebook chat to them.

Like Us on Facebook.
PC KIDS & ACTIVITIES

We know PC kids love being active. In time, some activities may become too painful to enjoy, but while young it is wonderful for PCers to explore every kind of adventure and opportunity.

We thought we’d include a page of some of our adorable PC kids — doing things they love. We have a few ballerinas—but no photos.

PC WEBSITE STORIES

We welcome more stories of kids, teens, adults for the PC Website. If for the front page, please use a white background (no shadows). Other stories can feature as many photos as you’d like to include.

We’d love to feature stories of all that PC Kids achieve — and the touching process of the teen years as they grow larger and the pain increases — and the ways they manage to find new activities and new ways to manage and succeed.

Your Stories Are Amazing - Please Share Them
**Step Up For A Cure**  
Pachyonychia Congenita Awareness  
June 2014  
Fighting for a cure. Connecting & helping patients. Empowering research.

**PLEASE PARTICIPATE**  
Join with others around the world and join in PC Awareness 2014.  
PC is a very, very rare disorder. Only if everyone gets involved in some way will we succeed. Remember that you and your family are probably the only voice for PC in your area. Together we can raise awareness, raise funds and Step Up For a Cure for PC.

It’s as easy as 1, 2, 3!  
1. **Choose your action.** We ask every PC family to participate in PC Awareness 2014. Choose something you already know and like… or any action that will be fun for you, family and friends to help raise awareness and raise funds for PC. Your action may be LARGE or very small and may raise only $1 (or $100,000!) — the important thing is that you are the ‘heart’ of PC action where you live. No one can take your place — you are the headquarters this June for PC Awareness 2014, so please “Step Up For a Cure for PC” in your local area.

2. **Register your event with PC Project.** Send an email to info@pachyonychia.org to tell us YES you will Step Up For a Cure 2014. Then, post, comment and blog about your own action on the PC Facebook Events page. We will also advertise through Facebook, Twitter, our website and other social media outlets. We have prepared a flyer template and poster template so that you can just add your local details. You can then send by email or print, post, hand out or distribute as you wish.

3. **Report Your Success.** Please send a report and photos to tell what you did. This will help others who may want to use your ideas in the future. All funds collected should be submitted; if you have expenses you’d like reimbursed, please let us know. Our sponsor will match $2-for-$1 the money you send from your event so that your efforts will bring three times the amount earned.

**Keep It Simple and Make It Fun**—Having trouble thinking of something to do? Those who have succeeded say ‘realize it is really pretty simple.’ Choose something you know or like. Involve your family, friends, classmates, co-workers, neighbors, church groups, service clubs or others who will be glad to help you.

Here are ideas from others from PC Awareness efforts in 2012 and 2013.

2013 PC Awareness on Facebook  
2012 PC Awareness on Facebook  
PC Awareness Archive  

NEW—in 2014 we have prepared a Fact Sheet and Flyer for you to use. We’ll put in the information you send us about your event, send you the file to print and distribute.
Our PC Patient Community is World-Wide

Map Showing 535 Genetically Confirmed PC Patients in the IPCRR

Note: placement for USA is by zip code. Placement elsewhere is by country—not by specific location.

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<th>PC-K6b N=155</th>
<th>PC-K6c N=17</th>
<th>PC-K18 N=91</th>
<th>PC-K17 N=91</th>
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<td>155</td>
<td>91</td>
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</tr>
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</table>

Demographics of 535 individuals with genetically confirmed PC

535 have confirmed PC
134 have other disorders not PC

Details on 134 with disorders other than PC
(35—5%) genetically confirmed NOT PC
(1) AAGAB
(1) APS Type 1
(2) COL7A1
(10) Connexin 30
(5) Desmoglein1
(1) Desmoplakin
(19—3%) genetic testing in progress
(21—3%) waiting for sample collection
(16—3%) genetic testing suspended NOT PC
(22—3%) no testing; no samples NOT PC
(21—3%) no further testing NOT PC (psoriasis of nails, steatocystoma multiplex, fungal)

IPCRR GROWTH REPORT
1381 individuals - 770 families
Registered with PC Project as PC Patients
669 individuals - 413 families
Questionnaires, Photos, Physician Notes completed
30 Mar 2014

We are hoping these 669 will join the PC Registry and find if they have PC or another disorder.

An Overview of the IPCRR 2014
PLANS FOR A ‘FIRST EVER’ MAJOR CLINICAL STUDY OF PC

At the May 2014, International Pachyonychia Congenita Consortium (IPCC) Scientific Symposium, there was consensus that more needs to be learned about the basics of PC — beyond understanding the genetic mutation, we need to learn more about the nerves, blood vessels, sweat glands, other contributing factors that lead to PC pain, cysts and other features unique to PC which may provide additional treatment targets.

PC Project was charged with organizing and carrying out the following -
1. Gather from 60 to 100 patients with genetically confirmed PC—we need patients! we need patients!
2. Identify the scientific questions that need to be answered — we are gathering these questions.
3. Identify the exams/tests/sample collection necessary to answer — we are making these lists. These may include having biopsies from the affected areas of PC feet.
4. Identify the world’s leading experts and invite them to participate — we are inviting these experts.

WITH APPROVAL FROM PROF. IRWIN MCLEAN AND FRANCES SMITH,
WE HAVE DECIDED TO CONDUCT THIS STUDY AS PART OF THE
2014 PATIENT SUPPORT MEETING IN EDINBURGH, SCOTLAND
OCTOBER 26-28, 2014

To register or apply go to http://www.pachyonychia.org/news_events.php

We are obtaining additional scholarship funding to help additional patients attend this year. This will be one of the most important efforts every launched for PC research and to be successful we need a large gathering of PC patients willing to participate in the required exams and tests. We will provide more details each month — but we urge you to plan your time and register now so you will be able to attend. NOTE: Patients outside the USA may apply for travel funding assistance as needed. USA patients may attend in 2014, but travel assistance from the USA will not be provided as there will be a 2015 meeting in the USA and a follow-up to this 2014 study will likely be conducted for USA patients there.

NEW FRONT PAGE STORY ON PC WEBSITE
We’re sure you will enjoy the darling new photo and the great story of one family with a PC-K6a baby. We need more photos and stories for the PC website. Share your experience with PC — how does PC affect you? Quality of Life is immensely important as we move forward. For example, “PC doesn’t cause death—why is it important to find a treatment?” And, what different has PC Project made? These stories have an impact on donors, doctors and researchers.

NEW PUBLICATION. The April 2014 issue of The Dermatologist (a journal found in many dermatology offices) has a feature article on PC. This article was possible because Janie Youhas, an IPCRR member, contacted the journal and suggested they do a feature on PC. There have been nearly 600 hits on this article online in less than a month. To read the full article go to http://www.pachyonychia1.org/Bibliography/PDFFiles/Schwartz,M.(2014).pdf
Thanks, Janie, for being an active PC advocate!
If every PC family does something, we can make a difference around the world. Choose what you’d like to do and tell us so we can let others know. You will make a difference in raising awareness, in raising funds — and you will find that this effort will empower you and your family. Join hands with others around the world and do something for PC Awareness — you are needed!

The 2014 Fact Sheet file is attached to this PC NewsBrief which you print and use as a handout. Also, we will customize a poster for your event if you send details. Let us know your plans. Your idea may be just what helps someone plan an event. For an online event, we have attached a list of some of the fundraising website services and their fees. Let us know if we can be of help.

**Georgia, USA**—The family of Coraline Jennings (who will be one year old in October) have combined several activities for their PC Awareness efforts. They will have a Quilt Raffle (and the beautiful quilt top has been completed by Hannah Jennings, Coraline’s mom!). They have also arranged for a local newspaper interview about Coraline and PC.

**New Zealand**—Jo Brodie, active Mom of Flynn Brodie, has an ambitious Half Marathon planned for PC Awareness. She is promoting her event on Facebook featuring PC Project themes.

**Wales**—Julie Baker and her son, Timmy Baker, 6 who has PC, have started a small craft business, called Cinnamon and Timbit, making flower brooches and hair clips out of recycled materials. Sold locally at craft fairs and school fêtes and online through Facebook. Last year we raised over £400 for the PC Project and this year we have already raised well over £300! The venture has also given us great opportunities to speak to people locally about Timmy’s condition—we have even been featured in the local community magazine! We received this fantastic feedback from one of our customers in Canada which goes to show how little things can make a big difference: “My friend Suzie absolutely LOVED the poppy. She wore it three times in the week we were on holiday! I told her all about Timmy. She had never heard of the condition. I told her that was the problem - it IS so unknown. Thank you for making me the poppies. As I give them to my friends, we will slowly build awareness.”
IPCC ANNUAL SYMPOSIUM
The 2014 IPCC meeting was a very excellent success with presentations from many of the PC main researchers as well as presentations on related research. Those participating were from many countries including China, France, Germany, Israel, UK, Singapore, The Netherlands and USA.

This worldwide interest in PC research is truly remarkable. We are busily following up with research proposals for new projects and new collaborations instigated at this important annual scientific meeting for PC. (See page 1 for the PC Clinical Study suggestion which we will implement at the October Patient Support Meeting.) A meeting review is being prepared for publication to provide access to all researchers.

PUBLICATIONS ON PC
Continuing to publish articles on PC research in top-ranked journals is important and builds interest in this rare disease. Excellent published research articles are the best tools for patients to use in informing healthcare providers and specialists. A peer-reviewed published journal article has much more impact that a simple brochure.

FINDING PUBLISHED RESEARCH ARTICLES ON THE PC WEBSITE.
PC staff members search PubMed and other resources to identify articles which mention PC or related research or disorders. To provide easy access to patients and medical experts, these are linked on the PC website. From the www.pachyonychia.org homepage, click What is PC? or For Professionals. (‘How To’ next column)

The dropdown list from both “What Is PC” and “For Professionals” have a link to Published Research Articles.

Click on either link to access the Published Research Articles page.

The Research Articles page gives you full access to more than 600 publications on PC. The current best ‘select’ articles are listed in the column on the right with direct links. You can click and print these articles to use in increasing PC awareness. You can use the search boxes on the left to find articles by any author, by keyword (such as K17) or with the full title, You don’t have to fill in all the boxes. A useful feature is just to put in the year range (put in 2013 and 2014) and see what’s the newest. Please give us feedback.
VOTES ARE IN—NEXT PC PATIENT SUPPORT MEETING
JUNE 2015 --NYC/NJ AREA
We are grateful to nearly 100 USA PCers who voted in the survey. Thank you!

CLINICAL TRIAL UPDATE
The Phase 1b formal Clinical Trial being carried out for PC at Stanford University is continuing. All patients have remained compliant — and we are so grateful. This is not easy. Because it is a double-blind, placebo-controlled study, neither patients nor doctors know whether they are receiving drug or placebo — or if one or both feet are receiving drug or placebo. Early data in any study is often confusing and PC Project receives no information from the study. The results of this study will be known and available in late Fall 2014.

Two additional studies are being prepared. A presentation by Alain Hovnanian regarding Capsaicin injections has led to a possible 10-patient study centered in France. Since this drug targets neuropathic pain, more confirmation of which PC genes cause neuropathic pain is needed. Some of the other proposals are aimed at gathering this needed information.

Plans to formalize and bring consistency to the various botox treatments for PC are continuing. The mechanism of this in alleviating PC pain is not well understood and the reason it is sometimes effective and other times not is still unclear and being evaluated.

PROBLEMS FACING PATIENT ADVOCACY ORGANIZATIONS
Two problems facing several advocacy organizations were recently discussed on the Genetic Alliance blog. We are so grateful to each of you, that PC Project is not facing these challenging issues.

I. ‘PATIENT CHAT’ ACCESS.
While one of the goals of PC Project is “Connecting Patients,” we know from others of the problems when access is not monitored. Therefore, we have created two separate PC spaces on Facebook.

Pachyonychia Congenita Project Facebook organization page is a space where anyone (patients and others) can post. Julie Peconi, the wife and mom of PCers, is a volunteer who monitors and posts on this Facebook page.

We have some who post here asking for help. Most of the time, these individuals never respond to our emails. We believe many who ‘drop by’ and ask for help, really do not have PC. We also realize, others may just need time to develop trust in who we are and what we are doing. We would like to be of help and hope all who have PC will contact us directly through the PC website.

The PC Facebook Patient Chat is a closed group for PC patients. If you are participating in the IPCRR and have PC, you can join the PC Facebook Patient Chat where you can connect with others with your same PC type. The type of PC matters — at LOT! There are many patterns that we see across the PC types. You can evaluate these trends by checking the PC Data tab on the website where we update the data charts very month.

When we have requests to join the PC Facebook Patient Chat from those who are not participating in the IPCRR, we explain this is a closed group. We invite everyone who believes they have PC to participate in the IPCRR and take advantage of the free services to confirm their condition.

II. ‘Splinter’ groups. This refers to small groups of individuals who do not support the main community and create sub-groups with a specific focus. PC is so rare that if we do not act together, we will have nothing but ‘painful splinters.’ We are so grateful to the PC community for acting ‘as one.’ Thank you for your support.

Two examples of groups that have formed to support and not to ‘splinter’ are LeCoeur au Pied in France and PC UK at the University of Dundee.

We hope that other local groups may organize to provide specific local help (such as language needs) — but that we will always act ‘as one’ in planning research, in publishing quality articles with accurate and up-to-date information and in working towards a common goal of ‘finding a cure!’
PC Awareness 2014
Please send us information and photos from your PC Awareness 2014 activities. Each person who is part of the PC community is important — and every effort small and large helps us to move forward.

We are a tiny group, but we have big goals and a great need to succeed. Do something for June 2014 PC Awareness — and then let us know about it!

FROM HANNAH JENNINGS
• Just wanted to let you know so you can share with others that I created a hashtag for this month! I’ve already started using it on Instagram and would love to encourage fellow PCers to use it for their events this month. #PCAwareness2014

FROM ROSEANN & MIKE McGRATH
• Enclosed is the $180.50 raised from our 3rd Annual Garage Sale that Mike and I matched the funds = total $361.00. (And, PC Project will match for a grant total of $1083 from this effort. Thanks!)

Please Like Us on our public Facebook page and invite your friends to Like Us. This helps others find PC Project & events.

DO THESE FEELINGS SEEM FAMILIAR TO YOU?

FROM A PC MOM
• “On another note, my son has never really wanted to tell anyone about his PC so in the past I have not been able to really participate in Awareness Day but I do want to send out a letter or email to friends and family asking for donations this year. Do you have a letter that anyone has made that introduces the disease and asks for donation? (Yes. We did have a letter another family had sent out).”

FROM AN ADULT PCER
• “I'm not ready to go public about my PC yet. I retired early from my job because of the constant pain from walking the campus. Never told anyone as the reason why I retired early. Only a handful of my closest friends are aware of my PC. I understand the importance of bringing awareness for PC but I'm still too embarrassed about my PC. I'm still making excuses as to why I couldn't join some of the social events that were too difficult for me to participate due to PC. I enjoy and look forward to PC conferences because I feel completely comfortable and being supported by those who understand the syndrome. Making donations at the PC events and conferences is my way of showing my greatest appreciation—but I can’t yet show the defective genetic inheritance.”

We understand these feelings — and want to lovingly encourage everyone to speak up about PC when the time is right.

What do you think of this slogan?

With PC there IS pain, but there is no shame.

EDITORIAL FROM MARY
An example of a staff organization was recently shared with me by dEBra one of three organizations similar to PC Project but working for Epidermolysis Bullosa (another rare skin disorder).

• dEBra has a staff of nine
  Director
  Chief Development Officer
  Events and Communications
  Local Events
  Programs
  Finance
  Database Manager
  Nurse/Educator

• PC Project has
  Director—volunteer
  Assistant Director
  Bookkeeper—4 hours/week
We must hire more paid staff!

Total 360 paid hours per week
Total 44 paid hours per week
The corporate sponsors for dEBra are numerous and we need to engage more corporate sponsors for PC. Can you help us with that? See http://www.debra.org/sponsors for examples from dEBra website.

Also, on the deBRA website, you will see, that the events held for dEBra are numerous — and with the funding they now have a professional staff to help those events. We don’t have that staff, but we are just asking each PC patient or family to do something they can do in their own area or with their own family or associates.

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The estate planning by David Witmer had a tremendous impact this year. We hope each of you will consider adding PC Project to your estate planning. It will be important.

We must have additional staff at PC Project and to do that we have to raise more funds. It is that simple. We have been unable to hire anyone as yet — I think they see that there is a lot of work and very few hands available. We will continue to interview and find other staff to join our efforts.

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The budget for PC Project must include costs to comply with the regulations so that we can continue our mission efforts. Recently, PC Project saved more than six thousand dollars by filing state registrations ourselves with the help of a temporary clerk. In addition, we were able to save hundreds of dollars in fees through the willingness of PC families to act as ‘registered agents’ for PC Project in their states. Another example of how these oversight agencies affect PC Project is that the BBB changed their requirements so that we had to change the Chairman of the Board of Directors to a non-staff person. We are careful to comply with the laws in each location so that we can continue to provide active advocacy for PC.

We wish each of you could share a day with us at PC Project. So many different things happen here every single day. We’ll share with you just a few of some of our advocacy efforts.

Pachyonychia Congenita falls within a number of categories. It is (1) a skin disease, (2) a rare disorder, (3) a genetic condition. PC Project participates with at least one umbrella organization in each of these three areas.

1. Coalition of Skin Diseases (CSD). There are 15 member organizations. One of the largest member groups is National Psoriasis Foundation (NPF) with 135 million patients worldwide and revenue of $7.5 million (in 2012). One of the smallest member groups is PC Project with less than 10,000 patients in the world and a budget of $469,000 (in 2012). The goal of PC Project is to deliver the same services and research for PC patients that larger groups achieve.

2. National Organization of Rare Disorders (NORD). NORD has published information on 7000 rare diseases. This group works mainly on major, high level issues including legislative issues. Recently PC Project joined in NORD’s letter to Congress to oppose changes in the USA Orphan Drug Law which provides incentives for drugs for rare diseases.

3. Genetic Alliance. This organization provides many major resources to assist advocacy for all genetic diseases (not just rare and not just skin).
We have no outside funding for the PC registry, for the clinical trials, for the other studies and projects we complete. With more funding support we could achieve even more. Can you find outside donors for PC Project? Every $ helps all of our efforts!

**Registry Now Over 1400**

Beginning with 3 in 2004, we now have over 1400 patients in the International PC Research Registry. This is the amazing service that is helping our research efforts.

And, because of the participation by patients in the registry, we are at an all-time high in research interest. Here is an excerpt from a recent email which outlines some of the current projects —

“I am sending this special email to all PCers in the registry living in or near the USA. We have several wonderful opportunities. For the first time, we have a number of researchers and universities interested in conducting PC research. The proposals are amazing in that the specialists involved are waiving any fees/salary/payment to them and only bidding for the actual costs of the study materials and lab processing, etc. I will put more about these projects in an upcoming PC NewsBrief, but wanted to get started right away to let you all know how very important and wonderful it is to be at this point in our progress towards understanding PC and getting effective treatments.

**Biopsy Skin Samples**

We have several projects that require biopsies. Our plan is to gather a group of about 15 to 20 PC patients probably in Salt Lake City. We will cover travel costs and costs of the biopsy. We will coordinate the date (probably in August 2014.) Patients will enjoy a brief time together as well as the opportunity to donate the biopsy sample. Here are a couple of the projects currently waiting for biopsies:

1. Researchers at Johns Hopkins who specialize in pain and keratoderma want to study the effect of PC on nerves and other structures found in the skin to help identify possible targets for treatment. We need to collect at least 10 biopsies from PC-K6a patients. These biopsies will be entirely used for this project and the research will begin as soon as we have the biopsies.

2. Cell lines with primary keratinocytes and fibroblasts from PC biopsies. These will be kept in a ‘bio bank’ for use by researchers. Although some cell lines exist from biopsies donated, we want to have one full set of each type of PC which have been collected and processed in a consistent manner.

3. Options to create animal models (mice, fly) to move us more quickly forward in testing various options for treatment.

**Tape Stripping**

To collect skin cells. A tape strip circle is like a small band aid that is applied to affected and unaffected areas and then removed, placed in a tube and sent to PC Project. From this proteomic studies will be conducted at UC-Davis and other universities to understand exactly what happens in the skin for those with a mutation. We did a trial of this last year and the findings were very powerful. We want to now extend this project which involves collecting tape strips from six individuals (one each of PC-K6a, PC-K6b, PC-K6c, PC-K16 and PC-K17 and a normal control).

**Two Patient Support Meetings Now Planned**

Because of the large interest in PC research, we are holding a second Patient Support Meeting Paris, France on October 10-11. It will be a mini version of the PSM to be held October 28-30 in Edinburgh. We will use both of these meetings to gather important information for PC research. More details will be on the website shortly at www.pachyonychia.org/Events

**Clinical Trial Update**

We agree it would be great to know just how things are going. However, the clinical trial for topical rapamycin will not end until October — and then there is a 3-month ‘wash out’ period. As it is a double-blind (neither doctors nor patients know who has drug and who has placebo), the data will not be available until the trial is completed.

**Thanks! Thanks! Thanks!**

to the 15 patients who continue to be fully compliant, travel and show up for every visit, every blood draw, every photo, every diary entry. We are so lucky to have this group of patients working so hard on behalf of all PC patients all over the world. Wish we could give you each a big hug— please know we appreciate you so much.
June 2014 PC Awareness Month—Sharing Information About Pachyonychia Congenita Around the World

**PC Awareness** is about raising awareness and raising funds. The purpose is to empower each PCer and family around the world. Every idea that helps others know about PC is a good idea. Every effort to raise funds for PC research and support is wonderful and every penny matters. Use these ideas to see what you can do to raise awareness and raise funds in your own family or your own area. Everyone is important in our PC community. Please help.

**FLORIDA, USA**—My son is not comfortable telling everyone about his PC so I sent a letter to family and friends who already know about his condition telling them about PC a little bit more and telling them about PC awareness month and asking for donations. I used the sample letters from PC Project. (Family members have donated over $350 USD and learned about PC).

**WISCONSIN, USA**—Allison Block gets ready for the Block family 3rd Annual PC Bake Sale held in Wausau, WI during the Wisconsin Off Road Series Bike Race. (WORS is one of the largest bike races in the country.) They raised $855 USD at their 3rd Annual Sale.

They are able to share PC Fact Sheets with hundreds of participants at the bike race where the bake sale is held.

**FLORIDA, USA**—Please Support Kieren Eyles and Philip Gard in this August Bike Ride PC Fundraiser

**ENGLAND-SCOTLAND**—Kieren Eyles has organized a 500 mile bike ride from London to Edinburgh (500 miles in 5 days). Dr. Philip Gard is also riding so there will be two PCers on one event - certainly a first!!

They hope to raise about £7,000 to £8,000 ($12,000 to $13,700 USD), which will be useful for PC (research and support).

Below is the fundraising link with the dates (August 21—August 25) and other information. More than £1200 is raised already!

https://www.justgiving.com/KIEREN-EYLES/
WALES—Julie Peconi, Tom Baker, Timmy Baker shared this great email from their chiropodist after Julie sent PC brochures to her — “Thank you for the articles you sent. They have been distributed to the staff via email. Just wanted to let you know that I organized a cake sale for staff at coffee and tea time during our meeting yesterday, with cake provided by myself and a couple of colleagues and all donations to go toward your PC Project fund-raising. We raised £60 ($103 US dollars) for PC!”

FRANCE—Beatrice Wannamacher writes about the PC Chess Tournament “This friendly event was a success. Forty-five people came to play chess, others came for the raffle. We raised €810 ($1,102 USD). Two articles about Pachyonychia Congenita were published in the local press. We'll do another event in September, a book fair hosted by our small town library. Let's hope this will be a success.

GEORGIA, USA—Soon after their baby was diagnosed with PC, the Jennings family began to plan their participation in the 2014 PC Awareness activities in their community. They succeeded in great publicity with feature articles on PC in the local newspaper. And, the quilt raffle raised more than $4,000. The winning raffle ticket was drawn as part of Coraline’s First Birthday on 28 June 2014.

BRAZIL—Monica Costa hosted a family dinner! She writes: “Last Monday we had a family barbecue for the PC Awareness 2014, and we raised $150.00USD! It was a very pleasant afternoon with my family and Carlos' parents.”

Quilt Raffle a top fund raiser in 2014

New Jersey USA
The McGrath’s 3rd Annual Garage Sale raised $361USD.

Left: Birthday Girl
Right: A young helper puts tickets into the raffle tumbler.

Quilt raffle to raise money for PC Project

Coraline Jennings

BY MARY ANNE CARROLL
The Oconee Leader

Odds are a funny thing. They can fall phenomenally in a person’s favor, like when someone wins the lottery. Or, they can deal a hard hand.
NEW ZEALAND—Jo Brodie raised $410 NZD ($395 USD) with a half marathon run to promote awareness for Pachyonychia Congenita.

THE NETHERLANDS—Again Elise van der Laan-Kokx and family have been effective in PC Awareness and fundraising. She writes, “We have put a box for vouchers (donations) at the supermarket in the month June. We raised €325! Also we had some other donations that were in total € 115,50. So we raised now: € 440,55 (or nearly $600 USD). You can read it on our website

OHIO, USA—Ryan Bush posts PC information on his blog page

THE NETHERLANDS—Eveline Schloesser writes: “I wanted to share my PC Awareness project with you. Only my close family and friends really know what’s going on and I’m not used to sharing this with people, but I’m going to do it anyway. Thanks to you and all the fellow PC-ers I’m not scared anymore to tell everybody what I have :)! I have ordered key chains with the site printed on it. Its in the color of the PC logo! I think they’re pretty cool!”
PC VOLUNTEERS HELP PC RESEARCH
We are so grateful for the many who have answered our request for volunteers for the current research projects.

- A group of about 15 PCers (and some family members) will travel to Salt Lake City for biopsies on August 9, 2014.
- A group of 30 PCers are participating in collection of PC skin cell samples using ‘tape stripping.’

More details on these two studies will be in next month’s PC NewsBrief.

- A group of five PCers recently participated in a special ultra sound imaging session held at TransDerm in Santa Cruz. (See photos).

Above: Dr. Yuan Cao and Madelyn Low (TransDerm) take images of a PC foot using a special ultrasound technique. Below: Imaging a PC hand. Since 2005, PC Project and TransDerm have explored various types of imaging systems to find ways to better study and understand PC. We are always grateful for the patients and volunteers who participate.

CLINICAL TRIAL CONTINUES
The topical rapa trial will be finishing up in the next month and then a three-month ‘wash out’ period before results can be evaluated/released.

Please Like Us on Facebook
on our public Facebook page (not Patient Chat) and invite your friends to Like Us. PC Project Charity Organization Facebook Page is at —
https://www.facebook.com/pages/Pachyonychia-Congenita-Project/139161046150358

Only a little information is available on the public Facebook page. Be sure you access the more complete information at our website at www.pachyonychia.org.

SPECIAL IMAGING STUDY AT TRANSDERM

Above: Dr. Yuan Cao and Madelyn Low (TransDerm) take images of a PC foot using a special ultrasound technique. Below: Imaging a PC hand. Since 2005, PC Project and TransDerm have explored various types of imaging systems to find ways to better study and understand PC. We are always grateful for the patients and volunteers who participate.

Hot/Cold Survey Results. Thanks to all who participated in April.

Do you prefer hot weather/hot feet or cold weather/cold feet. Which lessens your pain?

- Prefer hot weather/hot feet: 12.1%
- Prefer cold weather/cold feet: 10.6%
- None of the above: 77.3%

With PC, there is pain. But there is no shame.
GIVE US SOME SKIN

Punch biopsy skin samples were taken from 19 volunteers on Saturday, June 9th. This included 16 PC patients and 3 ‘normal control’ subjects (husbands of PCers).

These skin samples will be used in PC research projects at a number of sites including Johns Hopkins University (Michael Polydefkis/ Mike Caterina) Neuroanatomy Study searching for understanding of PC pain, University of Michigan (Laure Rittie) 3-D modeling of PC cells to understand how PC mutations affect other structures within the skin such as sweat glands, nerves, etc. and TransDerm (Roger Kaspar) microarrays, drug development, drug delivery.

These patients travelled from

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to donate their samples.

WE ALL THANK YOU!

Here are some pictures of the ‘biopsy party’ which was like a ‘mini’ patient support meeting where everyone united in the cause to further PC research and ‘fight for a cure.’
GIVE US SOME SKIN (con’t)

Patients arrived on Friday, August 8 and gathered in Heber City at the Schwartz cabin. Always the most valuable part of any PC gathering is the connections between patients — learning, sharing, realizing that another person really understands PC. It was a beautiful day and we enjoyed a lovely dinner with everyone helping to set up and clean up — a real family feeling.

After dinner, there was a discussion about the details of the biopsy procedure for the next day. Then everyone went to the hotel for the night.

The clinic appointments started early Saturday morning. Dr. C. David Hansen opened his clinic just for this project. Thirty-eight biopsies were taken and prepared for the various studies.

After the biopsy, everyone gathered at David and Janice Schwartz’ home — where everyone could relax (put their feet up) and where again the comradery and sense of community was very evident.

More good food was enjoyed at lunch! Some enjoyed tours of the PC Project office or a drive up one of the canyons. Throughout the afternoon and evening patients went to the airport to return home.

We look forward to learning more about PC through the great contribution of these participants. Our thanks to all!

We have received wonderful emails from many of those who participated
in the ‘biopsy party’ We wanted to share this message as it captures the wonderful feeling of the event and also covers so many points that are important for each PCer.

“Thank you so much for bringing me to Salt Lake City. I was very happy to give the biopsy and hope that it will give some answers to questions that are out there.

I think the best part of the entire trip was getting to know all of you, seeing the office and meeting all the other PC guests. I was so blessed by the entire weekend!! I was so glad to get to know everyone and hope to come to the next meeting. I will gladly give a biopsy again whenever it is needed. I was especially happy to hear more about Pachyonychia Congenita and hope to learn more as time goes by.

One thing I was so glad to hear was about using a wheelchair on a really bad day or if I was going to the fair or when I needed to walk long distances. I have never used a wheelchair, but rather said I would stay home, sit on a bench or just sit in the van etc.

The other patients told me to not give up on myself and not worry about what other people say and just use a wheelchair. Well, I finally did!!

I spent a few days visiting with family before I flew home. My husband and two grandchildren (ages 12 and 13) picked me up at the airport. Then, we went to the county fair. The kids were looking forward to going so I told my husband about using a wheelchair. At the fairgrounds there was a wheelchair rental place near the fair entrance. I rode in the wheelchair and I actually got to see the entire fair!!! I wasn’t hoping to go home soon, or hurting so bad I wished I was at home. I met several people who wondered why I was in a wheelchair and I told them about my PC! I can’t believe I did that, and people were very understanding and asked questions etc.

I can not tell you how happy I am to have been able to meet such wonderful people this past weekend! Thank you”

**Wheelchair Survey**

We’d like to build a ‘fact base’ on wheelchairs for patients to access when they are considering obtaining a wheelchair for use when needed. Please email us at info@pachyonychia.org with your responses to these questions:

- What factors would you consider in choosing a chair?
- Do you have a recommended brand or style? If yes, please let us know.
- Do you have any contacts to get a wheelchair for a reasonable price?
- What is a good price for a wheelchair?
- Have you been able to have insurance cover any of the costs of a wheelchair?
- Other comments or suggestions for a PCer choosing a wheelchair for the first time?

**Tape Stripping Samples**

Thirty PCers have completed and returned their tape strip circles and are shipped to Dr. Robert Rice (University of California—Davis).

This is another research project to learn more about the mechanisms of PC which will lead to further research, understanding & interventions that may assist patients.

**GeneReviews 2014**

An update has been published for PC at GeneReviews, a respected online resource sponsored by the National Center for Biotechnology Information through the National Library of Medicine and the National Institutes of Health. GeneReviews are expert-authored, peer-reviewed disease descriptions ("chapters") presented in a standardized format and focused on clinically relevant and medically actionable information on the diagnosis, management, and genetic counseling of patients and families with specific inherited conditions. GeneReviews currently comprises 608 chapters — and one of them is on PC! NOTE:—this is one of the most respected online sources for professionals. You can print/copy this item and share it with the medical professionals helping you or to interest a new advisor/expert. We think you will also enjoy this information.

To effectively share information about PC with medical professionals, it is best to have a copy of one of the featured research articles from the PC website. Print and share the article and you will find it more effective than a pamphlet.
2014 Patient Support Meeting (PSM)
Edinburgh, Scotland
October 26-28, 2014

30 PCers registered to attend. We believe these meetings are extremely valuable — for patients to connect and learn from one another and for physicians and scientists to meet and spend time with a number of PC patients. The meetings have had an enormous impact on research progress and on individual lives. We would love to have you come and join us, but we need your help so that we can best plan the program. As soon as possible, please —

1. REGISTER for the meeting.
   (a) If this is your first meeting, the meeting fee is waived. You can apply for scholarship funding for hotel, travel expenses and family members fee.
   (b) If this is not your first meeting, you can apply for scholarship help for the meeting fee, hotel or travel costs.

2. REGISTER at the hotel.
   Please book direct with the hotel by September 29 (you don’t need to pay anything now — but we need to know you are coming in order to plan a great program!). You pay the hotel when you check in.

3. APPLY for any needed scholarship funding. Deadline to apply for scholarship is Monday, September 22. Pay what you can yourself so we can help as many as possible — but don’t let financial difficulty keep you home!

“I remember being very shy and uncertain about attending my first meeting. I was in shock when I saw that so many people had PC, because I thought that I was the only one who had it... The meetings helped me improve my self confidence. I was able to talk and share my pain without being judged. I kept in touch with people and I could always count on them when I needed help. I will always be thankful for everything the foundation has done for me, you have changed my life.”

The following article highlights an amazing PC Awareness Fundraising Event organized by PCers in the UK.

MISSION ACCOMPLISHED:
2,640,000 FEET FOR FEET
491 miles;
4379 metres of climbing.
£12,257 raised so far*
by Phil Gard, Race Participant

It was an interesting experience, nine riders and a support car driver. Kieren Eyles, his sister & friends & my wife, Mary, & me. The daily distances involved were greater than almost all of us had done before. The one rider who was used to this sort of challenge had a sore knee and only managed about a quarter of the trip. Most of the team are only occasional cyclists and were taken to their personal limits and a fair way beyond, completely rubber legs with 40 miles to go, being sick after tough stages etc. Kieren, event organizer, who has a nasty version of K6a, was virtually unable to walk after the first couple of days, Kieren Eyles, Event Organizer

30 PCers registered to attend.
being piggy backed or fireman lifted on and off his bike. Made us feel rather small in comparison.

Mary and I ended up doing the navigating, leading the group and playing sheep dog at the back, trying to keep people together and towing the weaker riders back on to the group. So we can feel that we did our bit.

We were incredibly lucky with the weather: sun and almost no wind for our climbs over the Pennines and up the Annan Valley from Moffat. Both beautiful climbs for those of us with the excess energy to look up from the tarmac. If we'd had any significant rain or wind we couldn't have made it; there wasn't anything in reserve. We did have a little word with a vicar friend before we left, so who knows?

It really was a crazy idea to take on this sort of ride, but we cracked it and it will stay in the memory for a long, long time. Many thanks for your support, we've managed to raise far more than I would have thought was possible a month ago.

*Funds will go to PC UK for patient support and research.

**PARIS PC STUDY MEETING**
On October 10-11, 19 French PCers will gather in Paris, France to participate in an examination and pain study. This is not a patient support meeting, but a similar opportunity will be available during the Edinburgh patient support meeting. We are grateful for the patients, scientists and physicians for their time and effort.

**CLINICAL TRIAL UPDATE**
The topical sirolimus trial participants are in the “wash out” period. They will travel one more time between September to December for a final visit. We expect to have the final results early next year.

**WHEELCHAIR SURVEY**
In the August 2014 PC NewsBrief, we asked some questions to start building a ‘fact base’ on wheelchairs. We would like to thank the four PCers who emailed us their responses. We have posted their comments on the PC Wiki at www.pachyonychia.org/wiki/index.php/Mobility_equipment#Wheelchairs

If you would like to contribute to the PC Wheelchair ‘fact base’ please email PC Project at info@pachyonychia.org.

**PC PROJECT GROWING**
In a prior NewsBrief, we said that PC Project was looking for additional staff. We are pleased to introduce new team members.

**Joanne Udy**— Bookkeeper (part time.) Thursday afternoons at PC Project begin with a bright smiling hello from Joanne. We are lucky to have Joanne and are grateful for her help with paying bills and keeping us in balance.

**Ellen McFarland**— Clerk/Adm Asst (part time). Ellen recently moved from Maine to Utah. She is preparing to attend the University of Utah for her Masters Degree. We are grateful for her enthusiasm and willingness to help with whatever is needed.

**4TH ANNUAL PC CHARITY GOLF TOURNAMENT**
For the past four years PC Project has hosted a Golf Tournament to raise funds for PC research and patient support. This is also for PC awareness in Utah.

All of the Board of Trustees members for PC Project participated this year either by donating, finding sponsors and donations, golfing, or volunteering at the tournament. We appreciate all their time and support.

This year the golf tournament was held on Saturday, August 23, 2014 at the Crater Springs Golf Course at the Homestead in Midway, Utah. It turned out to be a beautiful day despite an early rain storm.

There were 136 golfers. Many drove up the canyon early Saturday morning in a thunder storm with heavy rain to support the PC tournament. Here are just a few stories of those who attended.
• Chad Lewis (football Hall of Famer, who played for the Philadelphia Eagles and St. Louis Rams) is currently the Associate Athletics Director for Brigham Young University. Before golfing, Chad did a live interview about the PC Tournament for the Golf Channel.

• Roger Kasper, CEO of TransDerm Inc, travelled from California to golf. Roger invited other friends and even invited Pfizer’s local representative to golf at the tournament to further discussions necessary to move towards further development of the topical sirolimus drug.

• C. David Hansen, Dermatologist at University of Utah, invited other physicians to join him at the tournament.

• Lex Udy, Chair of PC Project Board of Trustees, doesn’t golf, but he sponsored a team and volunteered to be a spotter at the hold-in-one during the tournament.

These are just a few of the many wonderful people who came to the tournament. We are grateful to the golfers, donors, sponsors and volunteers for participating in the golf tournament and making it a success.

The next PC Golf Tournament is scheduled for Saturday, August 22, 2015. A tournament takes a lot of hard work, but it is worth more than the funds that are raised.

We hope that each of you will plan a local event or find your own way to spread PC Awareness. You don’t have to wait until next June — start planning today! You are the PC center in your own family, community, and area.
FINDING VIDEOS & PRESENTATIONS ON THE PC WEBSITE

Are you a PCer, a parent or someone with questions about caring for PC, living with pain, the science behind PC, or other queries?

As you may know, the PC website is a great resource for patients, families, and professionals. Many videos and presentations are available for free viewing by anyone through our website!

Videos ranging from very specific topics such as “Caring For PC - Keratoderma” to basics such as, “What is Pachyonychia Congenita?” are available and have been very helpful for patients and families. There are videos from past Patient Meetings including “Living with Pain”, “The siRNA Clinical Trial” and others. We would love your feedback. What one is your favorite? What topic would you like a video about?

Email to info@pachyonychia.org.

Follow these simple directions to access the online videos.

1. Go to the PC website (www.pachyonychia.org) and click on the link for “News and Events.” The link can be found either in the upper left corner of the home screen or from the drop down menu under “For PC Patients.”

2. On the right hand side of the News & Events page, scroll down and click the link for Videos & Presentations under the header: Videos & Presentations Archive.

3. Click anywhere on the image to start playing a video, or click on the title (for example: “Living with Pain”) to open the video in a new tab and much bigger screen.

All of the available videos are listed at the bottom of the page with links that also open the video.
PCer’s Challenge Raises $160

Like everyone else on the world wide web, Nancy Bohnsack watched as the ALS Ice Bucket Challenge took Facebook by storm. Then one day, after seeing a video clip about annoying cell phone habits, she was inspired to make her own challenge: she dared herself and seven friends to abandon their cell phones for just one day. For each friend who succeeded, she would donate $20 to PC Project.

Nancy’s challenge to her friends accomplished two things: it raised $160 for PC Project and educated a new group of people about PC and what life is like for individuals who have PC. Thank you, Nancy, for showing us all how we can each make a meaningful difference for PC.

This is a great example of something you can do with friends, family, or coworkers for our 2015 Awareness Month in June. Joining forces with those we care about to create better habits or kick the bad ones in the name of a good cause is twice the fun.

Clinical Trials
Topical Rapamycin Trial—participants are still in the “wash out” period. They will travel one more time between September to December for a final visit. We expect to have the final results early next year.

Tape Stripping Trial—Collection of samples for the tape stripping trial is complete. The lab partnering on this study has received all samples collected and is in the beginning stages of processing.

Blist er Fluid Trial—PC Project has begun working out details on a new opportunity to include PC patients in a study being conducted at the Queensland University of Technology in Brisbane, Australia that examines protein changes in different types of wounds.

Published Articles
Three new scientific articles on PC have been published. We encourage you to read and share to help promote education and awareness about PC.

Access these and other published articles on PC on our website HERE.

1. PCQoL: A Quality of Life Assessment Measure for Pachyonychia Congenita (Journal of Cutaneous Medicine and Surgery, 2014 August)
2. First Case of Pachyonychia Congenita in the Czech Republic (Dermatologic Therapy, 2014 August)

PC Project Updates
Last month we introduced you to new team members Joanne Udy and Ellen McFarland. This month we have grown a bit more and added one more person to our team.

Jennifer Rohn—Development Director (full time).
Jennifer is a Utah native who has worked in the nonprofit field for the past nine years. She holds a bachelor degree in Communication from the University of Utah and a Master’s of Professional Communication from Westminster College in Salt Lake City, UT.
Upcoming Events

Paris PC Study Meeting
October 10-11, Paris, France. Mary Schwartz will represent PC Project at this meeting where we are gathering 17 French PCers for an examination and pain study. This is an excellent opportunity for the PC community and we are grateful to the patients, scientists, and physicians who have made this a possibility.

2014 Patient Support Meeting
October 26-28, Edinburgh, Scotland. We are excited to announce that more than 40 PCers are registered to attend our annual patient support meeting. We have excellent opportunities scheduled for those participating and will report on meeting results in next month’s News Brief.

2015 Patient Support Meeting
Mark your calendars! Our 2015 Patient Support meeting has been scheduled for June 14-16, 2015, in Newark, NJ. Registration info and program details to follow.

PC Awareness Month June 2015
PC Awareness Month aims to empower each PCer and family around the world by coordinating efforts to raise awareness about and critical research funding for PC.

In 2014 we saw some amazing projects and heard heartwarming stories of communities all over the world coming together to support their friends, family, neighbors, and even strangers living with PC.

We encourage each of you to start planning now for how you will join us to make Awareness Month 2015 a grand success.

PC Project will be supporting your efforts with tools and resources for your planned activities. Submit your plans/suggestions/requests for our 2015 Awareness Month to Jennifer Rohn: jennifer.rohn@pachyonychia.org

Golf Tournament
The 5th Annual PC Charity Golf Tournament will be held on Saturday, August 22, 2015, at the Crater Springs Golf Course at Homestead Resort in Midway, UT.

Have you read the personal stories on our website of individuals living with PC? If not, Read Them Here. These PCers help us tell the world about PC and why it’s so important to keep supporting PC Project and the patients we serve as we fight to develop effective therapies, and eventually a cure.

Please consider adding your story. Every person who speaks up lends power to our cause.

Send your story to: info@pachyonychia.org

Send Us Feedback!
Let us know what you want to see in the PC News Brief. Send your suggestions to: info@pachyonychia.org
It is with great sadness that we share this tribute to Beatrice Wannenmacher, a long-time, beloved French ally of the Pachyonychia Congenita Project.

Beatrice first contacted PC Project in 2004 to start the enrollment process into the International Pachyonychia Congenita Research Registry and proceed with genetic testing. She was the 43rd person to enroll in the IPCRR registry.

Her clinical diagnosis suggested something other than PC; however, like PCers, Beatrice lived with pain every day with blisters over her entire body. Her genetic testing has been ongoing since 2004, and the McLean/Smith laboratory at the University of Dundee lab is still working to find the cause of Beatrice’s symptoms.

Despite this, Beatrice continued to be a steadfast advocate for PC and PC-like illnesses, while we at PC Project continued to look for a confirmed diagnosis for her. Her annual awareness events included bake sales, book fairs, and chess tournaments – which raised thousands of dollars for PC Project.

Beatrice Wannenmacher
1973 - 2014

Beatrice and a young chess opponent at one of the popular chess tournaments Beatrice planned for PC awareness.

PC supporters at a bake sale planned by Beatrice for PC awareness.

Volunteers at a book fair coordinated by Beatrice for PC awareness.
She served as Secretary for the French PC affiliate, Le Coeur Au Pied, alongside Sylvie Cierpucha, helping with organization and arrangements for several Patient Support Meetings in France. Several of you may have had the opportunity to meet her at one of the meetings in Scotland or France and benefit from her gentle manner, spunky spirit, extraordinary intelligence and ready friendship.

Over the last ten years, Beatrice has frequently served as translator on international calls coordinating efforts for research and meetings. Most recently, Beatrice served as an integral part of the planning for the Paris patient meeting, held October 10–11, 2014 and translated several critical documents from English to French. She saw the importance of research project.

Last May, PC Project set a goal to obtain full data sets for 50-100 genetically confirmed PC patients over the next year to assist our supporting physicians and scientists with ongoing PC research.

Data sets include the following:
1. Genetic—genetic testing through IPCRR.
2. Clinical—a full half-hour dermatological exam led by one physician.
3. Neurophysiological—pain study consisting of seven questionnaires and an hour long test with a pain specialist.
4. Histopathological & Molecular—information gathered by a biopsy.

The Paris meeting was the first of three meetings where full data sets will be collected from PC patients. Seventeen patients attended and participated in our data collection efforts at this meeting.

PC patients gather with Eli Sprecher, MD (4th from right) and Roger Kaspar, PhD (2nd from right) at the Paris meeting.

The information being collected from these data sets will be key in all future research and studies. This is an amazing undertaking that no other rare disease has done.

At the Patient Support Meeting next week in Edinburgh, Scotland, 35 more PC patients will complete full data sets. Combined with the 17 patients who participated at the Paris meeting and the others that will be collected at the 2015 Patient Support Meeting to be held in Newark, NJ, and we are well on our way to reaching our goal of 100 PC patients with full data sets.

With the Paris meeting concluding just hours prior to Beatrice’s untimely passing, her unwavering dedication to PC research and awareness will be acutely evident as we proceed with the subsequent two meetings that will finish out our data collection efforts for continued PC research.

It is in this spirit that we also recognize the many PCers who have volunteered to take part in the data collection efforts for our new research goals. These individuals give their personal time to travel, fill out multiple lengthy questionnaires.
naires, and complete full medical exams all with the goal of furthering basic knowledge of Pachyonychia Congenita which will lead to more effective research for PC.

Along with our patients, several passionate volunteers have been invaluable to the successful coordination of these efforts. Along with Beatrice Wannamacher, Sylvie Cierpucha and Youmna Tabet provided outstanding local logistical support.

And finally, none of our research would be possible without the countless hours, resources, and supplies donated by our team of expert physicians and scientists. The immense value of these contributions cannot be measured.

We’d like to specifically thank the Dr. Alain Hovnanian and the Imagine Institute for rare diseases for opening the Institute to us on Saturday and providing all the clinical facilities for this study.

And, we’d like to recognize the following researchers who made the study possible:

- Alain Hovnanian, MD (local site arrangements and clinical exams)
- Roger Kaspar, PhD, Scientific Advisor for the study (photos and assessment)
- Juliette Ly, medical student (pain study assistant)
- Hadas Nahman-Averbuch, PhD (pain study under direction of Silviu Brill and Ruth Defrin)
- Frances Smith, PhD (genetic analysis, patient organization, disclosures, and coordination)
- Eli Sprecher, MD, PhD, Chief Medical Officer for the study (clinical exams)

Thank you, again, to all of you, for your immense passion, dedication, and ongoing support as we continue our journey to discovering better treatments, and eventually, a cure for PC.
2014 EDINBURGH PC PATIENT SUPPORT MEETING
An amazing group of 44 PCers, plus their family members and more than a dozen physicians and Scientists—over 100 total attendees—came together in Edinburgh, Scotland for a successful 2014 PC Patient Support Meeting (PSM).

Irwin McLean and Frances Smith organized a wonderful meeting full of love, humor, research and PC support. In addition to Irwin and Frances, a special thanks to their team at the University of Dundee: Sara Brown, Michael Conneely, Robyn Hickerson, Declan Lunny and Neil Wilson for all their work on this meeting.

The main session included presentations by Sara Brown, Kieren Eyles, Philip Gard, Roger Kasper Irwin McLean, Laure Rittié and Frances Smith on a variety of PC topics. Other features at the meeting were equipment demonstrations showing some of the latest research techniques, a care discussion and patient group discussions for each PC type.

Kieren Eyles, Robyn Hickerson and Bob McLean took the teens out for a special adventure with “Extreme Carting”—and the smiles tell the story of a fun time! Under the direction of the leaders, Linda Campbell, Angela Evans, Stephanie MacCallum, and Louise Stanley, the younger kids had their own meeting full of activities, fun and games. The kids extracted DNA from a kiwi, made and presented a DNA chain to the adults, and had a special magic show.

Running parallel with the main program were the clinical and pain studies. Individual PCers had an opportunity to participate in the dermatological exam including photos and a pain study. They also completed seven pain questionnaires and updated their registry data as part of these sessions.

Identified in May 2014 by members of the International PC Consortium as a critical need for PC research, this “First Ever” major clinical study on PC has a goal of collecting full clinical and pain information on at least 60+ patients with genetically confirmed PC. The first section started at the Paris meeting early in October. The Edinburgh meeting was the second session and the final participants will be during the 2015 New Jersey Patient Support Meeting to be held June 14-16, 2015. Registration for the 2015 meeting will begin in December.

There are four parts to the major clinical study that are needed to have a full set of data for researchers to compare and learn from:

1. Genetic information—based on individual genetic testing results.
2. Clinical information—a full dermatological exam led by Eli Sprecher, MD who conducted all 22 (+12 from Paris) 30-minute exams assisted by physicians Philip Gard, Mary Sommerland, Edel O’Toole and Mozheh Zamiri,
3. Neurophysiological information—gathered under the direction of pain specialists Hadas Averbuch and Nirit Giva. Even when a fuse died in one of the pain machines they were able to get it fixed and still make time to see all the patients. The pain study portion includes questionnaires and two half hour exams.

PC Teens and leaders at “Extreme Carting” adventure during the PSM Meeting
4. Histopathological & molecular information—this information is from a biopsy and will be gathered from individual patients as this project is completed in the future.

This extensive data has never been consistently collected for PC and is a unique undertaking for such a rare disorder. It is an essential step in the pathway forward as we seek to find effective treatments and understand the variations across the PC syndrome.

A special thanks to Roger Kaspar, who not only updated us on PC Research, but took the photos of the 22 PCers for the study. Thank you to Coral Allen and those who donated to the craft sale and raffle that was held during the PSM to raise funds for PC research.

This meeting was supported by PC Project, PC UK, The Welcome Trust, and University of Dundee DGem. See pages four and five for a photo collage of the 2014 PSM.

CONNECT WITH PC PROJECT
If you have a question, problem, or need, the best way to reach PC Project is by email at info@pachyonychia.org, by telephone at 877-628-7300, or through the PC Connect with Us link on www.pachyonychia.org website.

PC SUPERHEROES - FUNDRAISING
Nathalie Kilchoer raised 6,000 Euro at her annual spinning marathon event (riding stationary bikes).

Beatrice Wannamacher’s sister, Delphine Wannamacher, presented PC Project with a 4,000 Euro check from Beatrice’s Memorial, book sale and chess tournament events that Beatrice raised before she passed away.

CARE TIP CORNER
Finding the right shoe(s) for PCers can be difficult. Most PCers have many pairs of shoes. The shoes need to be comfortable, breathable and flexible with just the right fit. At the recent PSM the following shoe brands were recommended: Clarks, Merrells, Tevas and Skechers. There seemed to be a generational split with younger PCers favoring flip-flop sandals over shoes. Put the word shoes in the search box on the website and the results will link to suggestions from many other PCers.

Care Tip Corner is a new feature for our PC News Brief. If you have a suggestion or care tip you would like to share, please email it to info@pachyonychia.org. The tips will also be added to the PC Wiki.

NOTE: Please remember that just because something works for one person, it doesn’t mean it will work for all. We share these tips to help each PCer find new options that might achieve better results.

PC RESEARCH
Topical Rapamycin—The Phase 1b Clinical Trial is nearly completed with only a few more patient visits in 2014. The data will be unlocked and results available early next year.

Tape Stripping—Robert Rice at the University of California, Davis is completing proteomic studies on the tape stripping samples provided by PC patients. Early results suggest a measurable difference in affected and unaffected skin. Our hope is that this may suggest clues to treating affected skin.

Blister Fluid—If you get visible blisters often and would be willing to have the fluid extracted for special testing, please email us: info@pachyonychia.org.

Biopsy Skin Samples—The processing of the biopsy samples collected in August is underway at Johns Hopkins University. Researchers are looking for neurological factors in PC.

Laure Rittié, University of Michigan presented 3D imaging of a PC sample at the 2014 PSM in Scotland. We are grateful for her volunteered time in analyzing PC skin and sharing her results with us.

PUBLICATIONS
Do you need to more effectively communicate with medical professionals? We encourage you to print and share articles from the PC website. These are found on the Published Research Articles page. On the right hand column are Featured Articles which will be especially important to share. We continue to actively work to publish information on PC in the leading journals as one of the most important methods to spread awareness and share accurate information on PC.

Laure Rittié, University of Michigan presented 3D imaging of a PC sample at the 2014 PSM in Scotland. We are grateful for her volunteered time in analyzing PC skin and sharing her results with us.
SHOPPING FOR PC
It’s that time of year when people around the world are gathering with friends and family to celebrate a wide range of holidays.

If your gatherings include a little shopping, consider doing yours online through any of the following organizations.

Without costing you a penny more than what you are already purchasing, you can help PC Project raise much needed funds to support our work.

Shopping with iGive returns an average of 3% of your purchase at more than 1,500 retailers back to the charity of your choice at no extra cost to you.

To get started, go to www.igive.com, fill out the short form, and choose PC Project as your charity of choice.

We have partnered with Goodshop so that now you can feel great about your online shopping!

Goodshop gives you the best coupons for thousands of stores like Target, Apple, Amazon, Petco and more AND a percentage of what you spend on virtually every purchase is donated to our cause! Plus, with the Goodshop app for iPhone and iPad, you can shop, save, and give on the go.

Go to www.goodshop.com, complete the quick signup form, choose PC Project as your charity of choice, and then shop away!

A sister site to Goodshop, Goodsearch donates to your cause just for searching the Internet.

Simply go to www.goodsearch.com, choose PC Project as your charity, and then search just like you would on Google, Bing, or Yahoo.

It’s well known that you can find pretty much anything you’re looking for on Amazon, and now, the stuff you buy can benefit the causes you love.

Go to smile.amazon.com, log in with your regular Amazon login info, select PC Project as your charity, and shop like normal.

0.5% of your qualifying purchases will be donated back to PC Project through the Amazon Foundation.

Find the links and how you can help on our website www.pachyonychia.org under the Donate/Help tab.

Find the links and how you can help on our website www.pachyonychia.org under the Donate/Help tab.
Eli Sprecher, Mary Sommerland, Edel O’Toole (below) Roger Kaspar and Mozheh Zamiri

The three “Scottish” runners for raffle prizes

Kids program—DNA chain and extracting DNA from kiwi (top two photos)

Coral Allan at the craft sale

Neil Wilson and Declan Lunny at microscope demos
Irwin McLean stole the cookie from the cookie jar.

Some of the amazing PCers at the meeting

(Below) Irwin McLean, Frances Smith, Robyn Hickerson, Eli Sprecher, and Hagit Matz
**PC Community: Viewpoint**

My name is Paolo Cognetti and I am from Italy. I have PC like my mom. She delicately told me what I had when I was a child and over the years she taught me how to deal with callouses, blisters and nails. She had to learn it by herself, “pagando il prezzo sulla propria pelle” – it means “paying the price for it personally” but we use the word “skin” in Italian which makes the expression even more appropriate for us PCers.

In Naples, in the ’50-’60s, no one knew about our skin condition and my grandmother who, despite trying hard and with the best intentions, could not help her much. Unlike her and thanks to her, I did not have to go through all of that. I consider myself very lucky.

Years later, I decided to have myself admitted to IDI for a week, a hospital in Rome that specialized in skin disorders. I gave my consent for several studies (blood test, biopsy, pictures, etc.): they suggested to try Neo-Tigason as a cure and I took it for a few months, but the results were inadequate and the side effects too many.

Back from Rome, out of curiosity, I Googled pachyonychia and I found the PC project website, but it was only in 2011 that I registered on the website and in 2014 that I finally filled out the IPCRR forms and photos. I really do not know why I kept procrastinating for such a long time, but, as you say, better late than never.

When I heard about the PC meeting in Edinburgh I was pretty excited, but as a film composer at the beginning of his career (let us keep our fingers crossed!), and having spent a lot of money to improve my setup I really could not afford it. Then, I applied for the scholarship and when Holly emailed me that they would cover all the expenses I was on cloud nine!

I was really curious to meet other people with PC, but I really underestimated to what extent I would be emotionally involved in the experience. It went way beyond my expectations. Seminars really shed light on something that, though I have lived with all my life, I barely know. It was really beautiful to be able to share my thoughts, concerns, and questions with other people that I was sure, for once, knew what I was talking about. I feel grateful for all the new friends that I now have in so many countries! And, last but not least, I went to Scotland for the first time and happily started a new hobby… whisky tasting!

I cannot wait for the next one and to meet you all again!

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**2015 PC Patient Support Meeting (PSM)**

The 2015 PSM will be held in Newark, New Jersey at the Renaissance Newark Airport Hotel beginning in the afternoon on Sunday, June 14 and ending with a lunch on Tuesday, June 16.

We plan to conduct the final set of dermatologic exams and pain study tests throughout this meeting for those patients with PC-K6a and PC-K16. We encourage those patients who live in North and South America to attend this meeting.

Registration and additional information on the meeting is available at pachyonychia.org/news_events
What is a Full Body Dermatological Exam?

Some people have wondered about the dermatologic exam that was done in France, Scotland and is scheduled for next year in New Jersey. Here is the answer:

Patients who participate receive examinations in a private room where they replace their regular clothing with a medical gown.

Two doctors are present for the exam and will explain the process before the exam starts. Once the exam begins the dermatologists look closely at all of your skin.

Typically they start with palmar plantar skin and then look at other skin on your body, including cysts. They look closely at your finger and toenails, your scalp and hair, inside your mouth, ears and eyes. The doctor will lightly touch the skin the entire time. A special magnifying glass or a light/lamp may be used to better observe a certain area or spot.

The exam takes about a half hour. Once the dermatologists are finished, a photographer will take medical photos to go with your exam notes. Photos include the face, sides of head, back of head, top of head, front of body, back of body, fingernails, palms of hands, toenails, soles of feet, tongue, and any cysts or lesions the doctor requested be documented.

We encourage those of you participating to ask all the questions you need and to speak to the exam doctors about any concerns you have to ensure you are comfortable for the duration of your exam.

Unexpected Benefits

Full body skin exams can identify skin cancers when they are most treatable. The amount of information and data gathered during this exam has never been done by another organization. We hope this information will help further research.

During the exams completed in Paris and Edinburgh, the doctors found atypical lesions on a couple patients which needed to be removed. Without this exam the PCers would not have known and it could have led to something worse.

Uniquely International

PC is rare and PCers are scattered across the globe. We have genetically confirmed PCers who have completed the IPCRR forms and joined the registry in over 40 countries. We are blessed to work with the top scientists and dermatologists all around the world. Because of this stretch across the world it is important to remember that something might be appropriate or standard in one country but may not be in another country. This is also true in the methods and behaviors for doctors and patients.

PC Research

PC research feels a little like trying to watch a flower bloom—A lot is going on, but it is difficult to see progress along the way. A few things we’re pleased to report:

Clinical Exam and Pain Study

Data is being entered for evaluation from the Paris and Edinburgh meetings. The plan is to continue these studies in Newark—IF the data from the first two meetings shows promise of leading to new understandings and research opportunities.

Cream Delivery of siRNA in Mice

A new paper was recently published by the McLean/Smith lab showing evidence of effective cream delivery of siRNA. A grant proposal has been submitted for a collaborative effort with Trans-Derm on this project.

Botox Injections

We continue to collect information from patients on successful and unsuccessful treatment with botox. As well as seeking to negotiate funding for a formal study.

Publications

Pachyonychia Congenita: An Overview was reprinted in Consultant 360 (October 2014; 54(10)) from the article originally published in The Dermatologist (April 2014). Consultant 360 is a journal for primary care physicians with a large readership.

You can access this article on the PC website, print it and share with your medical professionals, dentists, school administrators, and others. Using peer-reviewed published articles is a very effective way to teach others about PC.
CARE TIP CORNER
What is the best way to treat deep cracks in the skin? We have had many suggestions from using different ointments (such as Neosporin, Aquaphor, and Blue Star Ointment) to using a lot of petroleum jelly to using super glue to glue the crack together.

One K6a PCer said: “I use Vaseline or generic petroleum jelly. Put it on feet before putting on socks each morning. Use after trimming and washing sores. Addicted to Vaseline. Keeps sores from snagging on socks and prevents drying and cracking which hurts.”

Email us about what you do for cracks? Also, if you have a suggestion or care tip you would like to share, please email it to info@pachyonychia.org

NOTE: Please remember that just because something works for one person, it doesn’t mean it will work for all. We share these tips to help each PCer find new options that might achieve better results.

PC SUPERHEROS
FUNDRAISING
The van der Laan family have been raising funds and awareness in any way they find. Last month, they sent a donation for $1,100 to PC Project. This time they had a stand at a second hand flea market and made some good sales.

Who’s Who

“Over the course of my first few weeks of life, my nails went from normal, newborn nails to deep yellow, then turned deep red, to brown, and then started to curl around 3 weeks old...My family found and reached out to PC Project...PC Project connected us to other PC families and gave us answers we were searching desperately for...My nails are now considered normal for me... (We care for them) using special tools to keep them at a comfortable length and ground down to a comfortable thickness...I have PC.” Who am I?

Find the answer and other stories on Pachyonychia.org—Do you have PC and are willing to share your story? Email stories to info@pachyonychia.org

SHOPPING FOR PC
Don’t forget to use the following links to do your online shopping from to help raise money for PC with no extra cost to you.

www.igive.com

www.goodshop.com

smile.amazon.com

YEAR END DONATIONS
During this time of year in the US, a lot of people are deciding where to make their year end donations.

Our Development Director, Jennifer Rohn, sent you an email with an attachment for our year end appeal. We invite you to share the attached appeal letter or to simply tell your friends, neighbors and co-workers to consider donating to PC Project:

www.pachyonychia.org/donate_help.php

Also, we have been posting reminders on Facebook, and Twitter. Please be sure to visit us and share with your friends.

THANK YOU!
We would not be where we are without each of you. Thank you for joining the IPCRR. Thank you for donating. Thank you for telling others about PC and raising awareness. Thank you for participating in surveys and clinical studies. Thank you for sharing your experiences with us. Thank you for answering our emails. Thank you for keeping your hope in PC Project alive. THANK YOU!

Ian, Elise & Mark van der Laan
PC Wiki: New Design

The PC Wiki has a new look. It is listed on the Living with PC drop down menu. There is now a side bar that lists categories. If you click on one of those categories you will get a page of topics. There are next and back buttons so you can read through each category without going back to the categories topic page.

There is a search box at the right top of the page. Put in a word and hit the enter button. The search window below will appear and then you can scroll down to see all results.