



Pachyonychia Congenita Project

Fighting for a cure. Connecting & helping patients. Empowering research.

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ANNUAL REPORT 2014

MISSION STATEMENT

The PC Project mission statement is Fighting for a cure. Connecting and Helping Patients. Empowering research. To find effective treatments for those suffering from Pachyonychia Congenita, PC Project actively supports several major functions:

- ◆ The International Pachyonychia Congenita Research Registry (IPCRR).
- ◆ The International Pachyonychia Congenita Consortium (IPCC).
- ◆ Annual Patient Support Meetings and other patient support services
- ◆ Participation and collaboration with other patient advocacy organizations

PAST YEAR'S ACCOMPLISHMENTS

International Pachyonychia Congenita Research Registry (IPCRR). The patient registry is the key to patient services. Through the registry each patient has an opportunity to contribute important data about their personal condition, receive a 30-60 minute telephone consultation with a qualified dermatologist and have free genetic testing completed with a saliva sample using a kit provided by PC Project and sent direct to the laboratory.

PC GROWTH	2012	2013	2014
Individuals	1192	1319	1480
Families	644	726	828

By the end of 2014, 161 new patients contacted PC Project for the first time. Genetic testing results were reported to over 70 individuals. Letters of support for school, work, insurance etc. were sent through out the year.



Dinner for PC at Genodermatoses Training

Genodermatoses Trainee Course

In January, PC Project sponsored six patients and Dr. C. David Hansen for the EADV Trainee Course on Genodermatoses in Innsbruck, Austria. Dr. Hansen provided an expert lecture on PC and the patients (representing four of the five PC genes) assisted in teaching about Pachyonychia Congenita. This type of 'grand rounds' is a goal at PC Project where the experience is beneficial for both the physicians and patients.

2014 PC Patient Support Meeting, Edinburgh, Scotland

The Patient Support Meeting was held in October and brought together over 100 attendees including 44 PCers and was co-sponsored by PC Project UK. Irwin McLean, Frances Smith and their team at the University of Dundee organized an educational meeting full of humor, love and support. There was a great opportunity for PCers to participate in the pain study and dermatological exam.



PC Teens and leaders at "Extreme Carting" adventure during the PSM Meeting

International Pachyonychia Congenita Consortium (IPCC). The IPCC is a group of physicians and scientists who collaborate in research for PC. Unique because it is organized by PC Project, rather than around a university, specific researcher, company or medical organization. Therefore, the focus is always on moving research forward for PC patients. At the May 2014 IPCC symposium in Albuquerque, New Mexico, the IPCC discussed the need for a clinical study that would require full clinical and pain information on 60 or more patients with genetically confirmed PC. There are four parts that necessary to complete the study.

1. **Genetic Information (Genetic Testing)**
2. **Clinical Information (Dermatological Exam)**
3. **Neurophysiological Information (Pain Study)**
4. **Histopathological and Molecular Information (Biopsy)**

This study began in October in Paris, France with 12 PCers and continued at the Edinburgh Patient Support Meeting (PSM) later that month with 20 additional PCers. Those who participated had a full body dermatological exam, two half hour pain exams and completed seven questionnaires. The final session of pain studies and dermatological exams will take place at the 2015 PSM.

Clinical Studies/Trials

Topical Rapamycin – This trial was started in January 2014 with 15 patients from the United States and Canada. PC Project developed the Photobox to use as a tool in the research. The Photobox was designed to get accurate pictures from every angle of the foot with consistent distance and focus. The final clinical segment of this study was in December. We are still waiting for the end results because of a three-month wash out period.



Tape Stripping – This study was conducted at UC-Davis for the purpose of collecting skin cells from each of the five genetic forms of PC and one control subject. This trial was also done in 2013 with positive feedback and powerful findings.

Special Imaging Study at TransDerm – Since 2005 TransDerm and PC Project have explored multiple types of imaging systems to find better ways to view and understand PC. They are now using a special ultrasound technique to get a better view.

Biopsy Skin Samples – Researchers that specialize in pain and keratoderma from Johns-Hopkins are currently studying the effects of PC on nerves and other structures of the skin. They have collected 10 biopsies from PC-K6a patients to help identify and target treatment possibilities.

Pain Study and Dermatological Exam –In October 2014, twelve patients were a part of a pain study at the Imagine Clinic in Paris, France and twenty patients took part of the same pain study in Edinburgh, Scotland.

FUNDRAISING

PC Awareness Month – The purpose is to empower each PCer and family around the world and raise awareness and funding. This year there were many different ways people of the PC community raised funds and brought awareness to the cause. Some examples included: bake sales, bike rides, a chess tournament, craft fairs, and many others.

Golf Tournament – This year our annual golf tournament was in August at the Crater Springs Golf Course at the Homestead in Midway Utah. There were 136 participants and others volunteering their time and support. This year all of the members from our Board of Trustees were able to attend. There was a team representing Pfizer, TransDerm Inc., physicians from the University of Utah, and Football Hall of Famer Chad Lewis who was able to do a live interview for the Golf Channel about the PC Project.



Dr. C. David Hansen (on right) with team

ROSTER OF BOARD MEMBERS

Board of Trustees. Board of Trustees meetings in 2014 were held April 11, August 22 and December 5. 2014 Board of Trustee members are:

- Lex L. Udy, PhD (CEO, retired) CHAIR
- Preston L. Cochrane (CEO)
- C. David Hansen, MD (Dermatologist)
- Roger L. Kaspar, PhD (CEO)
- David R. Owens, Esq. (Attorney)
- Janice N. Schwartz (PC Project Patient Advocate)
- Mary E. Schwartz, (PC Project Director)
- Craig T. Vincent, Esq. (Attorney)
- B. Jackson Wixom (Executive, retired)

AUDITED FINANCIAL STATEMENT SUMMARY 2014

Total Income	\$1,035,400
Program Expenses	\$ 404,951
Administrative Expenses	\$ 67,546
Fundraising Expenses	\$ 37,692
End of Year Net Assets	\$1,082,357
Donated services	\$ 194,315