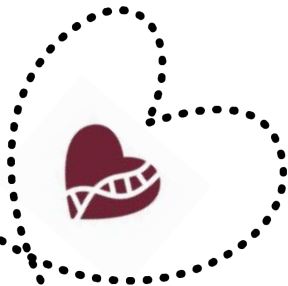


**INTERNATIONAL PACHYONYCHIA
CONGENITA CONSORTIUM (IPCC)**

12th Annual Symposium



Working together to
make a difference!



**May 5-6, 2015
Atlanta, Georgia**





Have an idea?
PC Project has an
open grant submission policy.
Apply Anytime.

2014-2015 IPCC Goal: Gather more basic science data on PC

What is being done to achieve the 2014-2015 goal?

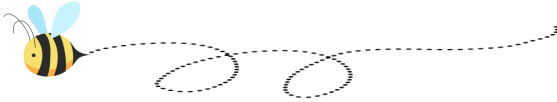
- More than 20 PC biopsies collected and analyzed
- Nearly 20 tape stripping samples gathered for a PC proteomic study
- Clinical Exams and Pain Study completed for 39 patients in sessions held in Paris and Edinburgh with a final session scheduled for 25 patients at the Patient Support Meeting in Newark, NJ in June 2015.

Thanks to the many experts who have helped achieve these actions including: Anna Bruckner, Phillip D. Gard, C. David Hansen, Alain Hovnanian, Roger Kaspar, Leonard M. Milstone, W. H. Irwin McLean, Edel O'Toole, Michael Polydefkis, Robert Rice, Laure Rittie, Frances Smith, Eli Sprecher, Maurice van Steensel, Mozheh Zamri. And, of course, a major thanks to the patients who made these efforts possible.

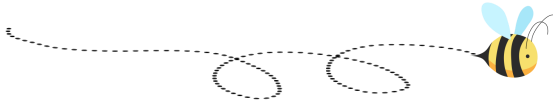
We welcome all collaborators and
invite everyone interested to join in our
effort to make a difference.

Patients are counting on us!

*“Today is the first day I discovered the name of the condition!
I am literally brought to tears at the thought of not being alone in this.”
~Rachel, Arkansas“*



*“I just wanted to thank you from the bottom of my heart for all the amazing work you are doing for all of us who have PC...To see so many researchers, clinicians... fight so hard for us to find ways to help alleviate the pain, and hopefully find a cure. I can't find the words to express how deeply it touched us and how much it helped me and my sister on so many levels. People who have PC suffer silently and we spend the bulk of our lives hiding our condition and telling the world we are fine, when in fact this disease is a deeply debilitating and crippling.
~Lisa, New York*



*“My daughter found information about this project and for the first time, we had hope. I have to take pain medication daily just to take a shower, brush my teeth and walk throughout the day.
My greatest hope is to find some relief...”
~Amy, North Carolina*

We invite all to join the IPCC
and work together to develop and deliver
PC therapeutics.



TUESDAY—May 5



1:30pm **Welcome—Eli Sprecher, IPCC Chair**
Sourasky Medical Center, Tel Aviv, Israel

Session Chair: **Dennis R. Roop**
University of Colorado, Denver, Aurora, Colorado, USA

KEYNOTE SPEAKER

1:35-1:55 *Cell Culture Models of Pachyonychia Congenita
for drug testing*

E. Birgitte Lane
Institute of Medical Biology Singapore, Singapore

2:00-2:20 *The Role of MicroRNA's in PC*

Andreas Berroth
TransDerm, Inc., Santa Cruz, California, USA

2:25-2:45 *PC Proteomics - Update*

Robert H. Rice
University of California Davis, Davis, California, USA

2:50-3:10 *Quantitative Analysis of Cutaneous Neuroanatomy in
Patients with PC*

Michael Polydefkis
Johns Hopkins University, Baltimore, Maryland, USA

3:10-3:30 **BREAK**

Session Chair: **Laure Rittié**
University of Michigan, Ann Arbor, Michigan, USA

3:35-3:55 *Using x-ray crystallography to correlate protein
structure with function in human skin diseases*

Christopher G. Bunick
Yale School of Medicine, New Haven, Connecticut, USA

4:00-4:20 *Other Hereditary Disorders of the Nail*

Amy S. Paller
Northwestern University, Chicago, Illinois, USA

4:25-4:45 *PLACK Syndrome: a new entity may mimic PC, EB,
Ichthyosis and Keratoderma*

Yong Yang
Peking University First Hospital, Beijing, China

5:45 pm **DINNER & ATLANTA BRAVES GAME**

Meet in lobby of Hilton Atlanta for bus ride to dinner and game.

WEDNESDAY—May 6

7:30 am—8:25 am BREAKFAST

8:30am **Welcome—Eli Sprecher**, IPCC Chair
Sourasky Medical Center, Tel Aviv, Israel

8:40-8:50 *PC Project Greetings*
Stephen Wittmer, PC Advocate
Sulpher Springs, Texas USA

Session Chair: **Leonard M. Milstone**
Yale School of Medicine. New Haven, Connecticut, USA

8:55-9:15 *Exploring neuro- and microbiology for symptom relief in PC*
Maurice A.M. van Steensel
University of Dundee, Dundee, Scotland UK

9:20-9:40 *Mouse models of Mal de Meleda and Prospects for Testing a Possible Therapy*
Stephen Young
University of California at Los Angeles, California, USA

9:45-10:05 *PPK Diagnosis Made Simple*
Eli Sprecher
Sourasky Medical Center, Tel Aviv, Israel

10:05-10:25 **BREAK**

Session Chair: **C. David Hansen**
University of Utah, Salt Lake City, Utah, USA

10:30-10:50 *Management of Chronic Foot Pain in a Pediatric Patient with Pachyonychia Congenita*
Sarah Tariq
University of Arkansas, Little Rock, Arkansas, USA

10:55-11:15 *Preclinical Studies of Topical mTOR Inhibitors*
Roger L. Kaspar, Yuan Cao, Tycho J. Speaker
TransDerm, Inc., Santa Cruz, California, USA

11:20-11:40 *Topical Sirolimus Therapy for Plantar Keratoderma in Pachyonychia Congenita*
Joyce M. Teng
Stanford University, Stanford, California, USA





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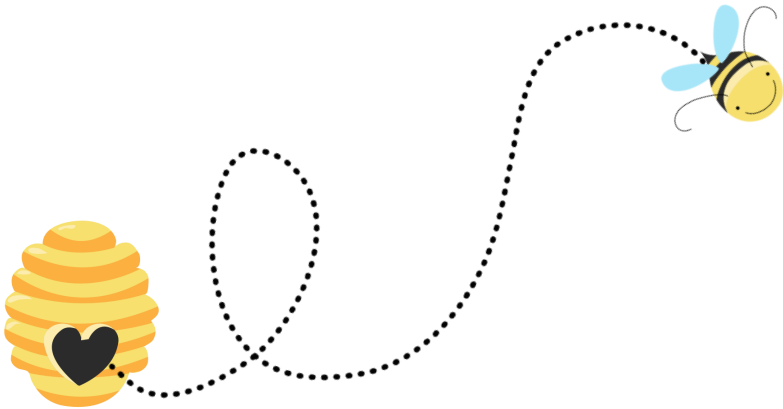
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INTERNATIONAL PACHYONYCHIA CONGENITA CONSORTIUM

Eli Sprecher, MD, PhD, IPCC Chair

IPCC STEERING COMMITTEE

W. H. Irwin McLean, Roger L. Kaspar, Frances Smith, Eli Sprecher



DIAGNOSTICS AND GENETICS TEAM

Webmeeting 1st Wednesday, monthly

FRANCES J.D. SMITH, Chair

Members

Philip Gard, C. David Hansen, Leonard Milstone, Edel O'Toole,
Eli Sprecher, Maurice van Steensel

RESEARCH AND CLINICAL TRIALS TEAM

Annual IPCC Meeting, Individual Collaborations, Webinars

ROGER L. KASPAR, Chair

The purpose of this team is to focus specifically on clinical trial development and assist one another in moving lab research forward to delivery to patients. The team membership fluctuates depending on specific needs and focus. Outside consultants are often involved with IPCC members where special expertise is needed. Many IPCC researchers have ongoing projects to develop therapeutics for PC. These are often featured at the annual IPCC meetings.

PHYSICIAN NETWORK

Annual IPCC Meeting, Quarterly Webinars

Led by the physicians on the PC Project MSAB, this network is open to physicians who treat or are interested in treating patients with Pachyonychia Congenita. The quarterly meetings are recorded for viewing online at any time and present current data and discussions on research and treatments for PC. We are working to have CME credit for some of these webinars.



*All are welcome to join the International PC Consortium (IPCC) and participate in one of the IPCC teams to collaborate in developing and delivering therapies for those with Pachyonychia Congenita.
If interested, please contact PC Project.*

PC PROJECT MEDICAL & SCIENTIFIC ADVISORY BOARD



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David Hansen



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