



IPCC WORKING GROUPS 2007-2008 FORMED AT 2007 IPCC ANNUAL MEETING

As more PC patients are identified in the PC Registry and as our research efforts expand, PC Project needs to effectively involve each IPCC member in collaborative endeavors.

Bio Marker Working Group. Developing measurable molecular endpoints for PC treatments.

Delivery Systems Working Group. Evaluating and developing delivery methods for PC treatments.

PC Animal Model Working Group. Identifying, defining, developing animal models for PC.

Clinical Advisory Working Group. Evaluate present PC treatments and prepare and review aids to assist physicians and patients in selecting options for care for PC.

Clinical Trial and Off-Label Studies Working Group. Assist in evaluating and carrying out clinical trials and approved off-label studies in PC patients.

PC Registry Working Group. Assist in preparing, editing, evaluating and reviewing information for publications based on data gathered through the PC Registry questionnaire.

PC Genetics Working Group. Prepare materials on the genetics of PC for publication on the website and in other forums for both patients and physicians. Include genotype-phenotype correlation studies.

IPCC Scientific Meeting Working Group. Plan and prepare for IPCC scientific meetings including identifying objectives and means of achieving objectives

Patient Support Meetings. Plan, prepare and participate in Patient Support Meetings including organizing, hosting or providing presentations.

_____ **Other.** What other PC Working Groups do you suggest?

Bio Marker	Animal Model	Delivery Systems	Clinical Advisory	Clinical Trial & Off Label Studies	Registry	Genetics	2008 Scientific Meeting	2008 Patient Support Meeting
Hickerson Robyn	Chen Jiang	Chen Jiang	DiGiovanna John	Fleckman Phil	Goldgar David	Bale Sherri	Leachman Sancy	Chen Jiang
Leachman Sancy	Del Rio Marcela	Del Rio Marcela	Fleckman Phil	Hull Peter	Leachman Sancy	Goldgar David	Kaspar Roger	Hickerson Robyn
Kaspar Roger	Foldvari Marianna	Foldvari Marianna	Irvine Alan	Irvine Alan	O'Toole Edel	Leachman Sancy	Milstone Leonard	Leachman Sancy
Leigh Irene	Gonzalez Emilio	Gonzalez Emilio	Leachman Sancy	Leachman Sancy	Mary Schwartz	Kaspar Roger	Xue-Jun Zhang	Kaspar Roger
McLean Irwin	Leachman Sancy	Hickerson Robyn	Leigh Irene	Kaspar Roger		McLean Irwin		McLean Irwin
Milstone Leonard	Kaspar Roger	Leachman Sancy	Milstone Leonard	Milstone Leonard		O'Toole Edel		Milstone Leonard
Hickerson Robyn	Larcher Fernando	Kaspar Roger	O'Toole Edel	O'Toole Edel		Smith Frances		O'Toole Edel
	Milstone Leonard	Larcher Fernando	Paller Amy	Paller Amy				Smith Frances
	Roop Dennis	Milstone Leonard	Spechter Eli					
		Roop Dennis						

Grey names are potential members not yet confirmed. **Bold** names are working group leaders for 2008. Some have accepted and others are 'nominated...' All groups have received initial emails. If you have not heard from your working group OR to join a group or groups, please email PC Project at work@pachyonychia.org. THANKS!

International Pachyonychia Congenita Consortium Members - June 2007

- Carol Oh Adib MD, St. Lucia, Australia
Diane R. Baker MD, Portland, OR, USA
***Sherri J. Bale** PhD, Gaithersburg, MD, USA
Eulalia Baselga MD, Barcelona, Spain
*R. Ralph Bradley MD, Salt Lake City, UT, USA
Fleming Brandrup MD, Odense, Denmark
Anette Bygum MD, Odense, Denmark
Thomas D. Cain DPM, Snellville, GA, USA
*Mario R. Capecchi PhD, Salt Lake City, UT, USA
Roman Carlos MD, Guatemala City, Guatemala
Julide T. Celebi MD, New York, NY, USA
Jiang Chen MD, Houston, TX, USA
Bernard Cohen MD, Baltimore, MD, USA
Christopher Contag PhD, Stanford, CA, USA
Pierre Coulombe PhD, Baltimore, MD, USA
Loretta Davis MD, Augusta, GA, USA
Marcela Del Rio PhD, Madrid, Spain
John J. DiGiovanna MD, Providence, RI, USA
Jon A. Dyer MD, Columbia, MO, USA
Robin A.J. Eady MD, London, UK
Tony Egan MD, Drogheda, Ireland
Mark J. Eliason MD, Salt Lake City, UT, USA
Ervin H. Epstein MD, San Francisco, CA, USA
*Philip Fleckman MD, Seattle, WA, USA
Scott Florell MD, Salt Lake City, UT, USA
Marianna Foldvari DPharmSci, PhD, Waterloo, Canada
Emilio Gonzalez PhD, Santa Cruz, CA, USA
Doug Grossman MD, Salt Lake City, UT, USA
Jennifer Hand MD, Rochester, MN, USA
*C. David Hansen MD, Salt Lake City, UT, USA
Robyn Hickerson PhD, Santa Cruz, CA, USA
Alain Hovnanian MD, PhD Toulouse, France
Peter Hull MD, Saskatoon, Canada
*Olga Igoucheva PhD, Philadelphia, PA, USA
Alan Irvine MD, MRCP, Dublin, Ireland
Brian Johnston PhD, Santa Cruz, CA, USA
Marcel F. Jonkman PhD, Hanzeplein, The Netherlands
Aleksj Kansky MD, Ljubljana, Slovenia
***Roger L. Kaspar** PhD, Santa Cruz, CA, USA
Brandi Kenner-Bell MD, Chicago, IL, USA
Paul A. Khavari PhD, Stanford, CA, USA
*Gerald G. Krueger MD, Salt Lake City, UT, USA
*Markus Landthaler PhD, New York, NY, USA
E. Birgitte Lane PhD, FRSE, Singapore, Singapore
Fernando Larcher PhD, Madrid, Spain
***Sancy Leachman** MD, PhD, Salt Lake City, UT, USA
Irene Leigh MD DSc FRCP, London, UK
Rudolph Leube MD, PhD, Mainz, Germany
*Alfred S. Lewin PhD, Gainesville, FL, USA
Haihui Liao MD, Dundee, UK
Colette D. Lieber MD, Mayway, NJ, USA
Susan Bayliss Mallory MD, St Louis, MO, USA
***W. H. Irwin McLean** DSc, FRSE, Dundee, UK
Ross McLeod MD, Calgary, Canada
Jemima E. Mellerio MD, London, UK
Brandie J. Metz MD, Orange, CA, USA
Bozena Michniak-Kohn PhD, Piscataway, NJ, USA
Lloyd Mitchell MD, Bethesda, MD, USA
***Leonard M. Milstone** MD, New Haven, CT, USA
Celia Moss MD, Birmingham, UK
Colin S. Munro MD PhD, Glasgow, UK
Brian Nickoloff MD PhD, Chicago, IL
Edel A. O'Toole MD, London, UK
Amy Paller MD, Chicago, IL, USA
Phoebe Rich MD, Portland, OR, USA
Todd Ridky PhD, Stanford, CA, USA
***Dennis R. Roop** PhD, Denver, CO, USA
Elizabeth Rugg PhD, Irvine, CA, USA
Matthias Schmuth MD, Austria
Michael Seidman PhD, Bethesda, MD, USA
Robert A. Silverman MD, Fairfax, VA
*Frances J.D. Smith PhD, Dundee, UK
Mary K. Spraker MD, Atlanta, GA
Eli Sprecher MD, Haifa, Israel
Carl Swartling MD, Uppsala, Sweden
Jean Y. Tang MD, PhD, Redwood City, CA, USA
Jouni Uitto MD, PhD, Philadelphia, PA, USA
*Maurice van Steensel MD, PhD, Maastricht, Netherlands
*Kyonggeun Yoon PhD, Philadelphia, PA, USA
Xue-Jun Zhang MD, Hefei, China
Yiwei Zhao PhD, Dundee, UK
Pingyu Zhou, Shanghai, China

* = Founding Member IPCC

Bold = Medical & Scientific Advisory Board member

= Chair, IPCC

