











IPCC NEWS

International Pachyonychia Congenita Consortium

Thanks! to IPCC members for your on-going support for PC Project

-  PC Project brochures distributed at ACMG by Drs. Bale & van Steensel.
-  Letters written & PC brochures sent to all PC patients tested and to referring physicians by Drs. McLean & Smith (more than 150 distributed).
-  Cells sent from Dr. McLean to Dr. Landthaler for tests with siRNA.
-  Grant proposals reviewed by IPCC members.
-  News articles received from Drs. Chen, McLean and Kaspar.
-  Sample genetic testing forms received from Dr. Bale
-  Referrals to other clinicians and researchers by many IPCC members
-  Emails, guidance, advice, encouragement from many IPCC members!

Some PC Project actions since February Symposium

- (1) Initiated a patient message board on the website. More than 50 PC patients/families are now in touch with PC Project.
- (2) Completed questionnaire and submitted for IRB approval.

JID 2004 PC Symposium Proceedings Publication

We have approval from the JID to publish the 2004 PC Symposium Proceedings. Of course their editors will review material prior to final acceptance and publication.

PC Project has agreed to fund this effort with a grant of \$25,000.

Now, dear friends, we are counting on you to respond to this opportunity and work together to produce a valuable and definitive publication on PC.

We have transcribed and reviewed all of the presentations and all the discussions. At first we had hoped these would be a basis for the JID articles. This is not the case.

Although the transcripts may not be useful in preparation of the published articles, these materials have been very helpful in forming PC Project goals (see page 2), in revising our Grant funding approaches, and in developing the vision for the JID publication.

Sancy Leachman will coordinate this project and she has used the transcribed Symposium materials to develop an approach and outline for the publication. The PC Symposium proceedings will be the definitive publication on PC. It will be complete and comprehensive — a valuable reference tool for scientists and clinicians.

We need your support and the collaborative effort of all IPCC members to accomplish this goal. Sancy will contact you shortly regarding this JID publication.



IPCC members meet the challenge

If you would like a copy of the transcription of your presentation (unedited and phonetically typed!) please request via email from Mary.Schwartz@PC-Project.org.

PC Project Grant Award Announcement at SID Conference April 28, 2004

We have selected the SID conference as the venue to announce the 2004 PC Project Grant Awards.

The grant proposals are currently being reviewed by several IPCC members.

The approach to funding

grants was revised during discussions at the 2004 PC Symposium. We asked each applicant to request only those funds necessary so that we can fund more grants and undertake collaborative approaches.

We are grateful that sev-

eral IPCC members have found outside funding for specific activities which will benefit PC research and some research is already moving forward.

Thanks! Thanks! Thanks!





PC Project
 2386 East Heritage Way
 Suite B
 Salt Lake City, UT 84109

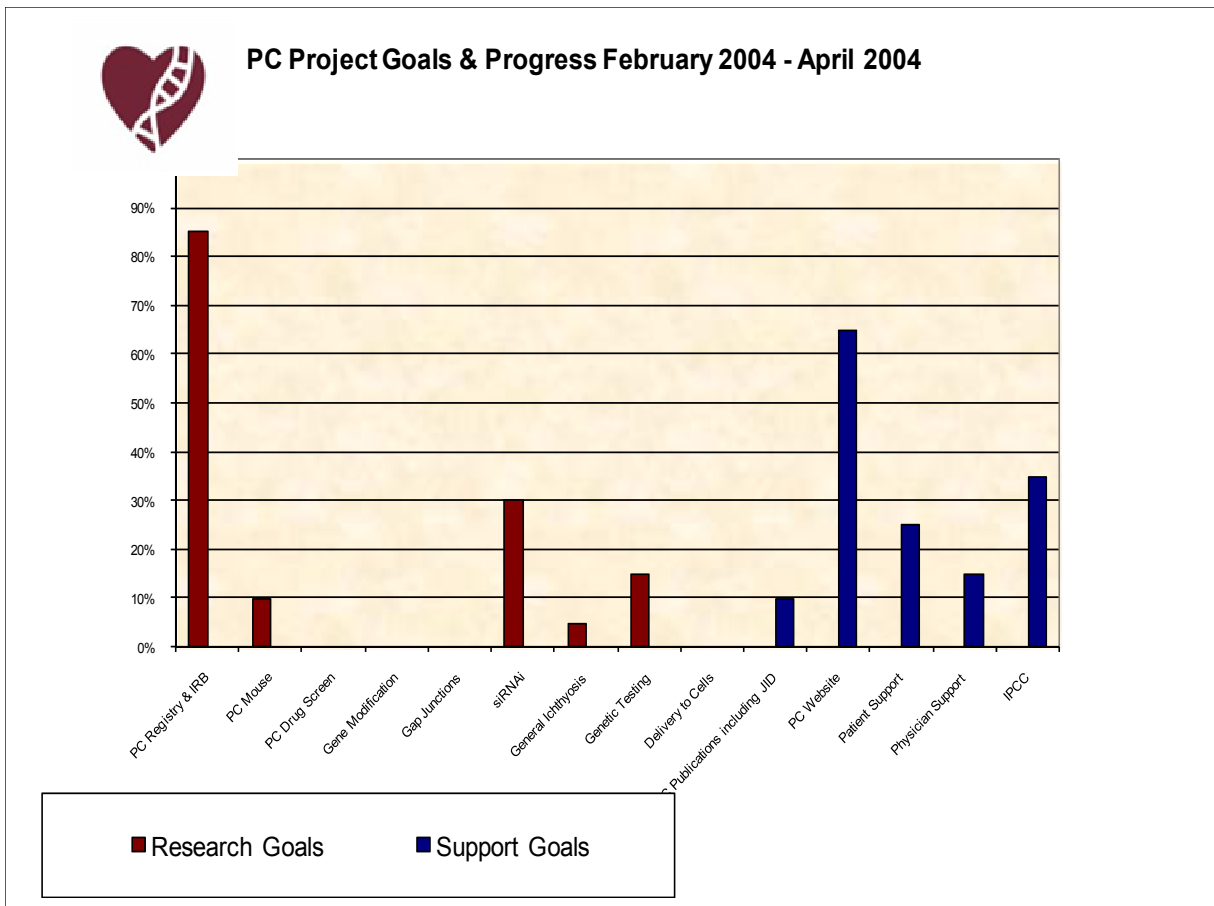
Phone: 877-628-7300
 info@PC-Project.org

**We're on the web at
www.PC-Project.org**

IPCC Founding Members & 2004 Symposium Attendees

Sherri Bale, Ph.D.	Roger Kaspar, Ph.D.	Frances Smith, Ph.D.
Ralph R. Bradley, M.D.	Gerald G. Krueger, M.D.	Bhaskar Thyagarajan, Ph.D.
Mario R. Capecchi, Ph.D.	Markus Landthaler, Ph.D.	Maurice van Steensel, M.D.
Jiang Chen, M.D.	Sancy Leachman, M.D. Ph.D. ¹	Pauline Wong, Ph.D.
Philip Fleckman, M.D.	Alfred S. Lewin, Ph.D.	Kyonggeun Yoon, Ph.D.
C. David Hansen, M.D.	Irwin McLean, Ph.D., D.Sc.	
Olga Igoucheva, Ph.D.	Leonard M. Milstone, M.D.	
Aleksej Kansky, M.D.	Dennis R. Roop, Ph.D.	¹ Organizer/Chair

Next IPCC Meeting — May 3, 2005 New Orleans (prior to the 2005 SID Conference)



PC Project has received IRB approval through WIRB.