



Pachyonychia Congenita Project

Pachyonychia Congenita (PC) is an ultrarare, dominant negative genetic skin disorder which causes blistering on soles and palms, thickened fingernails and toenails, white growths on the tongue, cysts and other painful and disfiguring symptoms. PC is a great model disease and success by PC Project not only means success for PC patients but will open the doors for many other disorders.

PC Project, a public charity, was founded in 2003 and has pursued three major efforts focused on development of therapeutics for PC Patients.

1. **Basic and Translational Research.**

- The International PC Consortium (IPCC) was formed in 2004. Members shared funding with nine seed grants involving full collaboration in sharing resources and reagents. The IPCC holds annual PC scientific meetings and is seeking NIH funding through a C.O.R.T. grant focused on PC.
- IPCC Symposium Proceedings were published by *The Journal of Investigative Dermatology* (October 2005).
- A partnership was formed with a biotech firm, TransDerm, Inc., to bring PC therapeutics to clinic as quickly as possible.

2. **Patient Support.**

- Four Patient Support meetings have been in the US and abroad which provided an excellent opportunity for patients to meet others with PC and for clinician interaction with PC patients.
- Publications include a 12-page Patient Booklet, a brochure for Medical Professionals & Scientists, and a General Brochure.
- The PC website has up-to-date information for physicians, clinical researchers and patients including a Patient Message Board for patient communication and a bibliography with PDF files of nearly 600 articles related to PC.

3. **Clinical Research.**

- An IRB-approved PC Research Registry provides a comprehensive questionnaire, a physician consultation and genetic testing.
- At the Patient Meetings, patients enthusiastically participated in sample collection including tape stripping, genotype/phenotype studies, confocal and digital imagery, etc.) These efforts have provided essential basic findings to establish clinical trials.

2386 East Heritage Way, Suite B, Salt Lake City, Utah 84109

Phone 877-628-7300 • Email info@PC-Project.org

www.PC-Project.org