Understanding PC Project

Training Session 2
Pachyonychia Congenita Project

USA = 501(c)3 Public Charity [2003]
Europe = Scottish Charitable Incorporated Org SCIO [2016]

International PC Research Registry
IPCRR

Patient Registry
Genetic Testing

Mission Statement

Fighting for a cure. Connecting & helping patients. Empowering research.
Discovering PAIN in Pachyonychia Congenita

International PC Research Registry IPCRR

IPCRR - PC Project
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Salt Lake City, UT 84109
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Phone: 877-628-7300 (toll free)

QUESTIONNAIRE

Thank you for being part of the IPCRR and for completing this questionnaire. Through the registry, information will be gathered so that physicians and other scientists can more effectively study PC and actively seek a cure for this disease.

We believe it will take about one hour to complete the questionnaire. You may finish it all at once, or start and stop as you wish. You may skip any question which you do not wish to answer or which is unclear to you. You will have an opportunity to discuss your responses with a physician in your telephone consultation.

There are six sections in the Questionnaire.
Section 1. IDENTIFYING INFORMATION ................................................................. Page 2
Section 2. DIAGNOSIS ....................................................................................... Page 4
Section 3. FAMILY HISTORY ............................................................................ Page 6
Section 4. PHYSICAL FINDINGS ....................................................................... Page 7
Section 5. TREATMENT AND CARE EVALUATION ....................................... Page 17
Section 6. PATIENT PHOTOGRAPHS ............................................................... Page 22
International PC Research Registry 2004-2016

Discovered PAIN is the most common feature of PC
Genetic Testing
PC Project has obtained genetic testing for more than 1000 patients through the IPCRR. Tests cost approximately $2000-$2500.

Factual data is now available to researchers on those patients with confirmed PC.

IPCRR data available at www.pachyonychia.org
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Other services --
Patient Newsletters
Patient Support Meetings

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International PC Consortium
IPCC

Collaborative research
Publications
Clinical Trials

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