



Pachyonychia Congenita Project

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The International PC Research Registry (IPCRR) is the only registry established specifically to gather data from those with PC. The IPCRR has received approval from the Western Institutional Review Board (WIRB Study #1057496). The Registry consists of: (1) a detailed Questionnaire; (2) a clinical consultation; (3) referral for genetic testing when appropriate; (4) free genetic testing with results provided to the patient and referring doctor(s) as authorized; and (5) genetic counseling.

To refer someone for the IPCRR, please make a copy of this form, provide contact information and mail to the above address. Or, if you prefer, contact us by telephone or email.

Publications

PC Project makes available at no cost the following educational publications:

____ 2 page pamphlet on Pachyonychia Congenita for Medical Professionals and Scientists

____ 12 page booklet for PC Patients (WIRB approved)

Please indicate the number of copies needed and include your contact information below.

Your Name _____

Address _____

City, State, Zip/Postal Code, Country _____

Phone _____ Email _____

Referral for IPCRR

Patient Name _____

Address _____

City, State, Zip/Postal Code, Country _____

Phone _____ Email _____