THIS MEETING WAS SUPPORTED BY

Pachyonychia Congenita Project

PC Project UK

wellcome trust

PACHYONYCHIA CONGENITA PATIENT SUPPORT MEETING

EDINBURGH 2014

BEST WESTERN CAPITAL HOTEL
26TH-28TH OCTOBER 2014

MANY THANKS
European PC Patient Support Meeting 2014

Best Western, Edinburgh Capital Hotel,
187 Clermiston Road, Edinburgh EH12 6UG

Local organisers:
Frances Smith, Senior Research Fellow, University of Dundee
Irwin McLean, Professor of Human Genetics, University of Dundee
Nikoletta Patourgia, Meeting Secretary

Meeting Programme

Sunday 26th Oct
17.30   Registration - Linda Campbell, Stephanie MacCallum & Louise Stanley
18.30   Drinks reception
19.00   Dinner
  Welcome to Scotland – Irwin McLean
  Introduction to PC Project – Holly Evans
  Clinical studies - Eli Sprecher

Monday 27th Oct – morning session, Irwin McLean, Chair
09.30   PC and the family of keratin disorders – Irwin McLean
10.00   Finding mutations in genes – Frances Smith
10.30   Break
11.00   Keratins - proteins that give skin their strength – Frances Smith
11.30   3D imaging of PC skin - Laure Rittié
12.00   Poster viewing/microscope demonstrations - Declan Lunny, Neil Wilson
12.30   Lunch

Monday 27th Oct - afternoon session, Sara Brown, chair
14.00   Care discussion – question & answer session - Sara Brown, Phil Gard
15.00   Somatisation, Stigma and Support - Kieren Eyles
15.30   Break
16.00   Patient discussion session - PC mutation groups
17.00   Free time
18.30   Drinks reception
19.00   Dinner
21.00   Scottish music, whisky tasting and informal chattering

Alternative programme:
09.30-12.30  4-11 year olds – Linda Campbell, Holly Evans, Angie Evans, Stephanie MacCallum & Louise Stanley
09.30-12.30  Teen discussions - Robyn Hickerson
14.00-17.00  4-11 year olds – Linda Campbell, Holly Evans, Angie Evans, Stephanie MacCallum & Louise Stanley
17.30-18.30  4-11 year olds - Magic show

Tuesday 28th Oct – morning session, Roger Kaspar, chair
09.30   Research in Dundee – Irwin McLean
10.15   Break
10.45   Therapies for PC – Roger Kaspar
11.30   PC Project - Holly Evans
12.00   PC Project UK Fundraising ideas/events – Frances Smith & Irwin McLean
12.15   Comments, feedback and discussion
12.30   Lunch and close of meeting

Alternative programme:
09.30-12.30  4-11 year olds - Linda Campbell, Holly Evans, Angie Evans, Stephanie MacCallum & Louise Stanley

PC Project UK – Homemade gifts will be on sale through out the meeting