PACHYONYCHIA CONGENITA PATIENT SUPPORT MEETING

Friday, 3-4 September 2004

Swallow Hotel
Dundee, Scotland

Sponsored by PC Project
Courtesy of Dr. Irwin McLean

SPECIAL THANKS TO

JOHN DART, DIRECTOR
DEBRA UK
BERKSHIRE, UNITED KINGDOM

SANCY LEACHMAN, M.D., PH.D.
UNIVERSITY OF UTAH
SALT LAKE CITY, UTAH, USA

W.H. IRWIN MCLEAN, PH.D., D.SC.
UNIVERSITY OF DUNDEE
DUNDEE, UNITED KINGDOM

COLIN S. MUNRO, M.D., FRCP
SOUTHERN GENERAL HOSPITAL
GLASGOW, UNITED KINGDOM

EDEL O'TOOLE, M.D.
QUEEN MARY, UNIVERSITY OF LONDON
LONDON, UNITED KINGDOM

FRANCES J. SMITH, PH.D.
UNIVERSITY OF DUNDEE
DUNDEE, UNITED KINGDOM

MAURICE A.M. VAN STEENSEL, M.D.
UNIVERSITY HOSPITAL MAASTRICHT
MAASTRICHT, THE NETHERLANDS

P R O G R A EM M

FRIDAY 3rd September
7-10 pm Social gathering in Foyer/Bar area, Swallow Hotel
Buffet dinner, snack food and drinks will be available

SATURDAY 4th September
8.00 am—10.00 am Full Scottish Breakfast served in Garden Restaurant

MORNING SESSION
9.00 am -10.30 am Arrivals, Registration, Coffee

10.30 am -10.50 am Welcome to Dundee - the city, the university
Irwin McLean, University of Dundee

10.50 am - 11.00 am PC Project Welcome
Mary Schwartz, Director

11.00 am - 11.10 am DEBRA UK
John Dart, Director

11.10 am - 11.30 am The clinical details of PC
Colin Munro, Southern General Hospital, Glasgow

11.30 am - 11.50 am Basic genetics for patients
Irwin McLean, University of Dundee

11.50 am - 12.10 pm The genes that cause PC
Frances Smith, University of Dundee

12.10 pm - 12.30 pm General Discussion

12.30 pm - 2.00 pm Buffet Lunch

AFTERNOON SESSION

2.00 pm - 2.30 pm PC Therapy Research
Sancy Leachman (outline international efforts)
Irwin McLean (outline Dundee efforts)

2.30 pm—3.30 pm OPEN DISCUSSION for patients, clinicians & scientists
Jan Schwartz, Discussion leader
Clinical panel: Colin Munro, Edel O'Toole, Maurice van Steensel, Sancy Leachman

Introduction—Jan Schwartz
Discussion topics:

1. The main challenges PC patients experience
   Diagnosis of PC – problems encountered
   Day to day problems – socially and physically
   Response paper: If you could change one PC symptom which one?

2. Treatments for PC
   Treatments that have been tried
   Treatments available (what works/what doesn't) for PC
   Response paper: What agents/actions do you use/take to make PC life better?

3. What can the PC Project do for me?
   What did you feel & think when you first found the PC Project website?
   Your hopes/expectations/suggestions
   Response paper: Clinical trials you'd be willing to participate in – care/cure

4. What can I do for the PC Project?
   Communication of ideas
   Clinical trials
   Patient-to-Patient support and communication
   Education and awareness
   Fund raising
   Registry/Questionnaire
   Response paper: What questions should be added to questionnaire?

3.30 pm - 4.00 pm Coffee, Tea and cakes
4.00 pm - 5.00 pm Finish patient photography and/or samples

SATURDAY EVENING SOCIAL PROGRAMME
6.00 pm BUS LEAVES SWALLOW HOTEL
6.30 pm Dinner followed by Drinks and Traditional Music
at Lands of Loyal Hotel, Alyth
11.00 pm BUS RETURNS TO SWALLOW HOTEL