

THE GENE CAUSING INCONTINENTIA PIGMENTI HAS BEEN IDENTIFIED

An event has occurred that many of us have been dreaming about. The gene which causes IP has been identified. I would like to tell the story of how this remarkable achievement came about. (continued on page 2 col. 1)

LETTER FROM THE EXECUTIVE DIRECTOR

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CELEBRATION DINNER

Members of the International IP Research Consortium

(Clockwise from left to right) Asmae Smahi, Susanne Emmerich, Alfredo Ciccodicola, Nina S. Heiss, Swaroop Aradhya, Sue J. Kenwrick, Richard A. Lewis, Hayley Woffendin, Annemarie Pouska, Michele D'Urso, Teresa Esposito, David L. Nelson, Tracy Jakins.

In December of 1999, the International IP Research Consortium met at the Hilton Hotel at Gatwick Airport in London, England. It was shortly after everyone realized that a mutation on the NEMO gene was definitely the cause of IP. The meeting began on Saturday morning and lasted all day. During this period, all the facts were reviewed and discussed. When it was dinner time, a large table had been set aside for the group in the dining room and the celebration began.

once again and the results were conclusive.

The excitement that overtook everyone is very hard to describe. It was the end of a very long and difficult journey.

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