

INCONTINETIA PIGMENTI CONFERENCE



NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

FEB 20-22

EMBASSY SUITES BY HILTON UPTOWN,
CHARLOTTE, NORTH CAROLINA

The conference will be a hybrid meeting with the keynote speakers and key researchers/ clinicians present onsite, with others invited to participate

CONFERENCE ORGANIZERS

Becky M. Abbott, MPH; J. Peter Campbell, MD MPH;
Connie Chen, MD; Mary Fete, MSN, RN, CCM; Ian Han,
MD

CONFERENCE SPEAKERS AND PARTICIPANTS

Becky M. Abbott, MPH; J. Peter Campbell, MD, MPH; Connie
Chen, MD; Mary Fete, MSN, RN, CCM; Ian Han, MD; Mary
Elizabeth ME Hartnett, MD, FACS, FARVO; Dorothy
Katherine Grange, MD; Sandra Montezuma, MD; Aliyah King,
BA; Reid Wilson, MD, PhD; Xi Chen, MD, PhD; Nancy Arias,
MD; Phillip Ehrich; Nicole Somani, MD, MPH; Eric Van
Otterloo, PhD; Saravanan Thangarajan, MDS, MBA; Maddison
Salois, BS; Markus Schwaninger, MD; Shirley Parraga, BS;
Jacques Monnet; Emily Cole, MD, MPH; Susanne Emmerich;
Teresa Faupel; Timothy Wright, DDS, MS; Philip Ferrone, MD;
Eric Nudleman, MD, PhD; Jeremie Rosain PhD, Audina
Berrocal, MD, Morton F. Goldberg, MD

AGENDA

THUR
20

7:00 PM Family Panel
7:30 PM Dinner & Introductions

FRI
21

7:00 AM Breakfast
8:00 AM Welcome
8:05 AM Goals and Expected Outcomes
8:10 AM Brief Presentations by
Participants
12:00 PM Lunch
12:30 PM Brief Presentations by
Participants
2:50 PM Clinical Recommendations
Working Groups
4:00 PM Advocacy / Patient Experience
4:30 PM Poster Presentations / Awards
5:30 PM Evening Reception
6:30 PM Dinner

SAT
22

7:00 AM Breakfast
8:00 AM Action Items and Deliverables -
Nomenclature, Screening
Guidelines, Registry/Database,
Multidisciplinary and Eye
Management
Recommendations
10:00 AM Writing Committee Discussion
11:00 AM Wrap-Up and Closing

The conference will bring together clinicians, researchers, and young investigators to present and discuss current approaches and future directions for translating science to therapy for incontinentia pigmenti (IP). Our goal is to advance our ability to diagnose and manage this rare disease through the development of screening guidelines, effective diagnostics, and novel therapies.

Topics to Advance

- IP Diagnosis and Screening
- Family Burden - Patient Perspective
- Clinical Features of Disease
- Sight Threatening Complications
- Current Practices and Treatment Protocols
- Genetic Aspects of Disease
- Molecular Pathways
- Development of Novel Therapies

Participants

Internationally recognized clinicians, researchers, and young investigators with expertise in developing and applying novel treatments in relationship to IP. Early career investigators are defined as postdoctoral fellows, graduate students, junior faculty (less than 10 years from obtaining terminal degree), and residents.

Registration
CLOSED

Conference
Sponsor



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