4th European Days of Albinism, 7-11 March 2018
Hurdal Vision and Activity Center, Oslo, Norway
Organized by Albinism Europe and NFFA

SCIENTIFIC and SOCIAL PROGRAM

Wednesday, 7 March 2018

Airport shuttle to Hurdalsenteret and Check in
18:00-20:00 Welcome dinner at Hurdalsenteret

Thursday, 8 March 2018

7:30- 8:30 Breakfast

8:45- 9:30 WELCOME SESSION
   Edel Krøll (4th EDA Coordinator for NFFA)
   Kjeld Christian Fjeldvig (President of NFFA)
   Antoine Gilsohn (Albinism Europe Coordinator)
   Benoît Arveiler & Lluis Montoliu (Albinism Europe Scientific Committee co-Chairs)

9:30-10:50 (I) FIRST SCIENTIFIC SESSION Chair: Benoît Arveiler

9:30- 9:45 Setting the stage: EDAs and Albinism
   Lluis Montoliu (Madrid, Spain) and Benoît Arveiler (Bordeaux, France)

9:45-10:10 Albinism: what’s in a name?
   Charlotte Kruijt and Maria Van Genderen (Zeist, Netherlands)

10:10-10:35 Molecular characterization of a series of 990 index patients with albinism
   Benoît Arveiler (Bordeaux, France)

10:35-10:50 Discussion

10:50-11:10 Coffee Break
11:10-12:30 (II) SECOND SCIENTIFIC SESSION Chair: Alessandra del Longo

11:10-11:25 Multidisciplinary approach of Italian Albino patients
Lucia Mauri and Alessandra del Longo (Milan, Italy)

11:25-11:45 Lessons of a day hospital: comprehensive assessment of patients with albinism in a European setting
Fanny Morice-Picard (Bordeaux, France)

11:45-12:00 Albinism in Denmark
Karen Grønskov (Copenhagen, Denmark)

12:00-12:15 Burden of Albinism: creation of a questionnaire
Charles Taieb (Paris, France)

12:15-12:30 Discussion

12:30-13:30 Lunch

13:30-15:30 (III) THIRD SCIENTIFIC SESSION Chair: Lluis Montoliu

13:30-13:45 Clinical and genetic study of albinism in Russia
Vitaly Kadyshev (Moscow, Russia)

13:45-14:00 Albinism in Israel: clinical and genetic characteristics
Anat Blumenfeld (Jerusalem, Israel)

14:00-14:15 Albinism in Brazil
Carolina Marçon (São Paulo, Brazil)

14:15-14:30 Albinism in Spain
Lluis Montoliu (Madrid, Spain)

14:30-14:45 Who has got albinism?
Isabelle Drumare (Lille, France)

14:45-15:00 Attempt of genotype-phenotype correlation in a cohort of molecularly confirmed OCA1 patients presenting the R402Q variant associated with a Tyr pathogenic mutation
Catherine Duncombe-Poulet (Caen, France)

15:00-15:30 Discussion

15:30-16:00 Coffee Break

16:00-18:00 (IV) FOURTH SCIENTIFIC SESSION Chair: Michael Hoffmann

16:00-16:25 Factors limiting vision in albinism and prediction of visual function later in life
Irene Gottlob (Leicester, United Kingdom)

16:25-16:40 Altered organization of the visual cortex in FHONDA syndrome
Khazar Ahmadi (Magdeburg, Germany)
16:40-17:05 Albinism. Perceiving the visual world with an alternative visual system
Michael Hoffmann (Magdeburg, Germany)

17:05-17:20 Albinism in Israel: clinical characteristics
Claudia Yahalom (Jerusalem, Israel)

17:20-17:35 Ophthalmologic and psychophysical evaluation of the visual system of individuals with albinism
Ronaldo Sano (São Paulo, Brazil)

17:35-17:45 Interest of OCT in nystagmus exploration: two case-reports of a late diagnosis of albinism, Dominique Brémond-Gignac (Paris, France)

17:45-18:00 Discussion

18:00-19:30 Dinner

20:00-22:00 FREE EVENING

21:00 Refreshments, coffee, cakes

Friday, 9 March 2018

7:30- 8:30 Breakfast

9:00-10:30 (V) FIFTH SCIENTIFIC SESSION Chair: Maria VAN GENDEREN

9:00- 9:25 Generation of new mouse models for investigating non-syndromic types of albinism through CRISPR gene-editing technology
Andrea Montero and Lluis Montoliu (Madrid, Spain)

9:25- 9:50 Variation in MFSD12 expression regulates skin pigmentation in African populations
Mickey S. Marks (Philadelphia, PA, USA)

9:50-10:15 Albinism in Africa: What can we learn from albinism frequency data?
Patricia Lund (Coventry, United Kingdom)

10:15-10:30 Discussion

10:30-11:00 Coffee Break

11:00-12:30 (VI) SIXTH SCIENTIFIC SESSION Chair: Fanny Morice-Picard

11:00-11:25 Reading in albinism
Frank A. Proudlock (Leicester, United Kingdom)

11:25-11:40 Analysis about visual acuity and binocular visual functions and the wavelet of children’s nystagmus in albinism
Dayong Bai (Beijing, China)

11:40-12:00 Mild syndromic forms of albinism: HPS3, HPS5, HPS6 and HPS8
Perrine Pennamen (Bordeaux, France)
12:00-12:15 Observations of two unrelated children with OCA phenotype resulting in HPS1 mutations
Dominique Brémond-Gignac (Paris, France)

12:15-12:30 Discussion

12:30-13:30 Lunch

13:30-15:00 Special Social Activity – Outdoor winter activities

15:00-15:30 Coffee Break

15:30-17:30 (VII) SEVENTH SCIENTIFIC SESSION Chair: Irene Gottlob

15:30-16:00 Oral Nitisinone in Oculocutaneous Albinism, type 1b (OCA-1b): Results of a One-year Pilot Treatment Trial
Brian Brooks (Bethesda, MA, USA)

16:00-16:15 Discussion

16:15-16:45 Consensus guidelines for the diagnosis and management of albinism
Mervyn Thomas and Irene Gottlob (Leicester, United Kingdom)

16:45-17:30 Discussion

17:30-17:45 Building of therapeutic education program for albinism: a multidisciplinary partnership
Smail Hadj-Rabia (Paris, France)

19:00-20:00 Dinner

20:00-22:00 SOCIAL EVENING

20:00-20:30 Official group photo by the conference photographer (in the gym)

21:00-21:30 Short film projection “Change your heart not my color” followed by discussion

Saturday, 10 March 2018

9:00-11:45 JOINT SESSION

9:00-10:00 Albinism and Human Rights
Ikponwosa Ero (Nigeria, Canada) – UN Independent Expert on the enjoyment of Human Rights by persons with albinism

10:00-10:30 Coffee break

10:30-10:50 Update on the activities of Albinism Europe
Antoine Gilsohn (Paris, France)

10:50-11:00 Thoughts from my 20 years serving the Albinism community
Mike McGowan - NOAH (Chicago, USA)

11:00-11:30 Summary of scientific presentations
Albinism Europe Scientific Committee
11:30-11:45 Discussion
11:45-12:00 CLOSING REMARKS
12:00-13:00 Lunch
             13:00 Shuttle bus to Oslo International Airport (for people leaving on Saturday March 10th)
13:00-18:00 FREE AFTERNOON – optional outdoor winter activities
18:30-20:00 Dinner
20:00-20:30 Short film projection “Moonlight Princess” followed by discussion with Nadine Nourney (Berlin, Germany), main actress and YPA participant
             21:00 Refreshments, snacks

OPTIONAL - Sunday, 11 March 2018

7:30- 9:30 Breakfast
8:30-10:15 FREE MORNING - optional outdoor winter activities
12:30-13:30 Lunch
             13:30 Shuttle bus to Oslo International Airport

With the financial support of the following organizations: