



## 4th European Days of Albinism, 7-11 March 2018

Hurdal Vision and Activity Center, Oslo, Norway

Organized by Albinism Europe and NFFA



**ALBINISM EUROPE**



## PROGRAM for REPRESENTATIVES OF ASSOCIATIONS

### Wednesday, 7 March 2018

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** (4<sup>th</sup> EDA Coordinator for NFFA)

**Kjeld Christian Fjeldvig** (President of NFFA)

**Antoine Gliksohn** (Albinism Europe Coordinator)

**Benoît Arveiler & Lluís Montoliu** (Albinism Europe Scientific Committee co-Chairs)

9:30-12:00 **JOINT SESSION WITH YPA PARTICIPANTS**

9:30- 9:45 Presentation of Albinism Europe

**Antoine Gliksohn**

9:40-10:50 Presentation of the different European associations

+ Self presentations of the YPA participants

10:50-11:10 *Coffee Break*

11:10-12:00 Special activity with YPA participants in the gym

12:00-12:30 **TRANSATLANTIC EXCHANGE**

Presentation of NOAH – followed by Q & A

**Mike McGowan** (Chicago, USA)

- 12:30-13:30 *Lunch*
- 13:30-15:30 **ALBINISM EUROPE WORKING MEETING**
- 13:30-14:30 Biennial report on the activities of Albinism Europe  
**Antoine Gliksohn**
- 14:30-15:30 Discussion on the future activities of Albinism Europe
- 15:30-16:00 *Coffee Break*
- 16:00-18:00 Discussion on the future activities of Albinism Europe
- 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*
- 9:00-12:30 **EXCHANGE OF EXPERIENCE**
- Selection of presentations and topics of discussion submitted by the associations
- 10:30-11:00 *Coffee Break*
- Selection of presentations and topics of discussion submitted by the associations
- 12:30-13:30 *Lunch*
- 13:30-15:00 **SPECIAL SOCIAL ACTIVITIES** – *Outdoor winter activities with scientists*
- 15:00-15:30 *Coffee Break*
- 15:30-17:30 **ALBINISM EUROPE WORKING MEETING**
- Discussion on the future activities of Albinism Europe
- 17:30-17:45 **SHORT PRESENTATION WITH SCIENTISTS**
- 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 people with albinism
- 10:00-10:30 Coffee break
- 10:30-10:50 Update on the activities of Albinism Europe  
**Antoine Gliksohn** (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 Discussions
- 11:45-12:00 **CLOSING REMARKS**
- 12:00-13:00 *Lunch*
- 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

## 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:**



**Norges Blindforbund**  
Synshemmedes organisasjon



International  
Federation of  
Pigment  
Cell  
Societies

[www.ifpcs.org](http://www.ifpcs.org)

International Federation of Pigment Cell Societies