“III European Days of Albinism Milan”

Milan, 7-8 April 2016

Program of Albino Patient Associations

Denmark, Finland, France, Germany, Italy, Norway, Spain, Turkey, UK & Ireland

Thursday, 7 April 2016

08:00 -08:30 Registration

08:30-09:00   General welcome

Chair: Tronconi E, Marocchi A, Gesu G, Representative of the Region, Masto R, Paschetta L

Parallel symposia: scientists, associations and symposia

Associations members only

09:00-13:30 Morning Session

• Presentations of new online Associations
• Reports on activities in different countries focusing on:
  ◦ Defense of the Albino rights
  ◦ Alliances with Public Administrations

11:45-12:10 coffee break

• Reports on activities in different countries focusing on:
  ◦ initiatives of social and scientific disclosure on this rare genetic condition
  ◦ Albinism and technologies

13:30-14:40   Lunch break

14:40-18.15 Evening Session

• “Wina” Project Presentation: mobility and new frontiers
• Albinism and European federation: state of art and new steps
16:00-16.30  Coffee/Tea break

- Europe and Africa: alliances and projects

Young People with Albinism Session

(Young Albino Patients only)

The second edition of the European YPA ("young people with albinism") will be held on April 6th to 10th, in Milan, by a co-financing from the European Commission in the Erasmus program. On this occasion, 25 young European Albinos, 18 to 30 years old, will organize a meeting during the IIEDA congress where exchange views on several aspects and difficulties of their daily life.

The following steps will be discussed:

- how to face challenges and overcome the limitations that their physical appearance and impaired vision can cause in personal relations, in study, trips, etc.
- What role do the new technologies play?
- What steps can be employed in the city to make them more welcoming and accessible to those suffering visual impairment?

These are just some of the questions that the boys will try to answer.
Friday, 8 April 2016

10.30 – 13.30 Plenary final session: scientists and associations together

- 10.30 -11:00 Summary of scientific presentations (Käsmann-Kellner B, Patrosso MC)
- 11:00 - 11.20 Summary of psycho pedagogical presentations (20 min)
- 11.20 -11.50 Summary of association’s presentations (30 min)
- 11.50- 12.00 Kid for kindness presentation (10 min)
- 12.00- 12.10 Dermatological Prevention presentation (10 min)
- 12.10-13.30 Global discussion/Presentation of leaflet/book on albinism for the general public/Proposal for the next meeting.