

Final program for the 2EDA Meeting

SATURDAY 5 APRIL 2014

08:30 - 09:00 Registration

09:00 - 09:45 General welcome, ALBA, ONCE authorities, Organizers

Researchers	Associations	Youth
09:45 - 11:30 Session 1: Human molecular genetics	09:45 - 11:30 Session 1: Introduction of new associations and projects developed since the 1EDA by European associations	9:45 - 11:00 Session 1: Self-introduction of all participants. 11:00 - 11:30 Visit the ONCE adapted facilities
11:30 - 12:00 Coffee/Tea Break		
12:00 - 14:00 Session 2: Molecular diagnosis of albinism	12:00 - 14:00 Session 2: Future project proposals to be developed in common by the associations	12:00 - 14:00 Session 2: Education. Introducing ALBA books. Sharing educational experiences in other countries. Optical aids and future improvements.
14:00 - 15:00 Lunch		
15:00 - 17:15 Session 3: Visual alterations in albinism	15:00 - 17:15 Session 3: Economic, organizational and social benefits of the creation of a European Federation of Albinism (Florian Gliksohn)	15:00 - 17:15 Session 3: Finding a job. Sharing what type of difficulties has been faced and the solutions found by every ones to overcome hurdles and problems and to find out jobs and develop at work the associated tasks. Overcoming barriers.
17:15 - 17:45 Coffee/Tea Break		
17:45 - 19:00 Session 4: Physiopathology of albinism	17:45 - 19:00 Session 4: Discussion about the creation of an European Federation of Albinism: process, structure and objectives	17:45 - 19:00 Session 4: Possible new meeting of youth with albinism. Programmes and activities that we would like to see implemented.
19:00 - 20:30 Free time		19:00 – 20:30 Visiting Valencia down town
20:30 - 22:00 Gala Dinner		20:30 - 22:00 Dinner

SUNDAY 6 APRIL 2014

09:00 - 09:45 Session 5: Skin alterations in albinism	09:00 - 10:00 Session 5: Meeting of European associations of albinism. Conclusions	9:00 - 10:00 Session 5: Collecting conclusions.
09:45 - 11:30 Session 6: Treatment of albinism	10:00 - 11:00 Session 6: 1st European meeting of youth with albinism: towards a new integration and employment policies. Conclusions for the Associations (Stefan Heidebrecht). 11:00 - 11:30 Discussion	10:00. Excursion
11:30 - 12:00 Coffee/Tea Break		
COMBINED SESSION: Researchers + Associations		
<p>12:00 - 12:50 Albino days experiences and rehabilitation medicine applied to albinism</p> <p>12:50 - 13:10 Summary of scientific presentations (Lluís Montoliu)</p> <p>13:10 - 13:30 Summary of associations presentations (Florian Gliksohn)</p> <p>13:30 - 14:00 Global Discussion</p>		
14:30 Lunch		
16:00 End of the 2EDA - Departures		