

## **ST** European Days of Albinism



October 27th & 28th 2012 - Paris, FRANCE

## **Preliminary program**

	Representatives	Physicians, researchers	
	of patients' organizations	and other scientists	
Saturday 27th October 2012			
9:00 9:30	Registration and Poster set up		
9:30 10:00	Opening session: Welcome & opening remarks by conference co-organizers		
10:00 11:30	Round table - Presentation of represented organizations	<ol> <li>Genetic and cellular aspects</li> <li>State of the art 1: genetic aspects:         OCA and syndromic forms (B. Arveiler)</li> <li>State of the art 2: cellular aspects:         Biology of melanosomes / melanogenesis         (V. Schiaffino)</li> <li>Functional studies of genes and mutations         Animal models (L. Montoliu)</li> <li>Genetic diagnosis:         Albinochip (L. Montoliu);         Next genetic sequencing perspectives (B.</li></ol>	
11:30 11:45	Coffee break		
11:45 13:15	Workshop – ideas of potential common projects and actions for patients' organizations as part of a collaboration at a European level	<ul> <li>Dermatologic aspects</li> <li>State of the art (A. Taieb)</li> <li>Talks selected from abstracts</li> </ul>	
13:15 14:30	Lunch and poster viewing		
14:30 16:00	3. <u>Presentation by Eurordis</u> – Networking between rare disease patients organizations in <b>Europe (A. Helm)</b>	<ul> <li>Ophthalmologic aspects</li> <li>State of the art (B. Käsmann-Kellner)</li> <li>RPE cells (G. Jeffery)</li> <li>Talks selected from abstracts</li> </ul>	
16:00 16:30	Coffee Break		
16:30 18:00	4. Conclusion of the 1 <sup>st</sup> day session – Drafting of a road map for a European collaboration between patients organizations	<ul> <li>4. Therapeutic aspects</li> <li>L-DOPA (L. Montoliu/G. Jeffery)</li> <li>Nitisinone (B. Brooks, NEI-NIH, USA)</li> <li>Using AAV with TYR or GPR143 for transiently correcting retina of albino rodents (E. Surace, TIGEM, Naples)</li> <li>Talks selected from abstracts</li> </ul>	
20:00	Gal	a dinner	

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	Sunday 28th October 2012			
9:15 10:00	1a Presentation by the scientific committee			
10:00 10:45	17 Tresentation by representatives of			
10:45 11:15	Coffee break			
11:15 12:45	2. Workshop – Improvement of clinical diagnosis on newborn, infants and older patients  ⇒ Needs and expectations of patients' organizations  Informal scientific workshops			
12:45 13:45	Lunch			
13:45 14:45	3. Workshop – Interactions between patients' organizations and European research laboratories  ⇒ Needs and expectations of researchers towards the role of patients' organizations			
14:45 15:00	Closing session			

## The 1<sup>st</sup> European Days of Albinism have received the support of the following sponsors:







