

Preliminary program

	<i>Representatives of patients' organizations</i>	<i>Physicians, researchers and other scientists</i>
Saturday 27th October 2012		
9:00 9:30	Registration and Poster set up	
9:30 10:00	<u>Opening session: Welcome & opening remarks by conference co-organizers</u>	
10:00 11:30	1. <u>Round table - Presentation of represented organizations</u>	1. <u>Genetic and cellular aspects</u> <ul style="list-style-type: none"> • State of the art 1: genetic aspects: <i>OCA and syndromic forms (B. Arveiler)</i> • State of the art 2: cellular aspects: <i>Biology of melanosomes / melanogenesis (V. Schiaffino)</i> • Functional studies of genes and mutations <i>Animal models (L. Montoliu)</i> • Genetic diagnosis: <i>Albinochip (L. Montoliu);</i> <i>Next genetic sequencing perspectives (B. Arveiler)</i> <i>Strategies for the identification of new genes and/or new mutations in known genes (B. Arveiler / F. Morice-Picard)</i> • Talks selected from abstracts
11:30 11:45	Coffee break	
11:45 13:15	2. <u>Roundtable with short presentations – Focus on common topics and on past and present projects of each organization</u>	2. <u>Dermatologic aspects</u> <ul style="list-style-type: none"> • State of the art (A. Taieb) • Talks selected from abstracts
13:15 14:30	Lunch and poster viewing	
14:30 16:00	3. <u>Presentation by Eurordis – Networking between rare disease patients organizations in Europe (A. Helm)</u>	3. <u>Ophthalmologic aspects</u> <ul style="list-style-type: none"> • State of the art (B. Käsmann-Kellner) • RPE cells (G. Jeffery) • Talks selected from abstracts
16:00 16:30	Coffee Break	
16:30 18:00	4. <u>Networking between organizations of people with albinism in Europe</u> <ul style="list-style-type: none"> • Short presentations: Past experiences of collaboration (Alba, Genespoir, Albinet, DFFA and NFFA) • Workshop: ideas of potential common projects and actions; Drafting of a road map for a European collaboration 	4. <u>Therapeutic aspects</u> <ul style="list-style-type: none"> • L-DOPA (L. Montoliu/G. Jeffery) • Nitisinone (B. Brooks, NEI-NIH, USA) • Using AAV with TYR or GPR143 for transiently correcting retina of albino rodents (E. Surace, TIGEM, Naples) • Talks selected from abstracts
20:00	Gala dinner	



Sunday 28th October 2012	
8:45 9:15	Welcome time
9:15 9:20	1. <u>Presentation of patients' organizations</u> • Overview of existing organizations of people with albinism in Europe F. Gliksohn
9:20 10:50	2. <u>Clinical diagnosis and lifelong medical care</u> • Milan Niguarda Hospital's Day Hospital M-C Patrosso • France's reference centers A. Taïeb (?) • Workshop: Improving clinical diagnosis on newborn, infants and older patients; What explains late diagnosis? → towards an earlier and more accurate diagnosis of albinism Organizing medical care for people with albinism → towards a global approach
10:50 11:20	Coffee break
11:20 12:50	3. <u>Promoting scientific research on albinism in Europe</u> • Overview of research on albinism in Europe (inventory of research programs) B. Arveiler • Genespoir's 15 years' experience B. Jouanne • Workshop: How can research on albinism be intensified? What role can patients' organization play?
12:50 13:50	Lunch
13:50 15:00	<u>Closing session</u>

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