

10 years of Service to Rare Diseases

Inserm

Institut national
de la santé et de la recherche médicale

15 February 2007

9:00 – 17:30



**Ministère de la Santé
et des solidarités**
Direction Générale de la Santé

French Ministry of Health - Ministère de la Santé et des Solidarités
14, avenue Duquesne, 75007 PARIS
Laroque Room

09.00	Participants are welcomed
09.30	Conference opens
	<i>Public Health Stakes for Rare Diseases Information</i> Dr Carole Cretin (Directorate of Health, Office for chronic diseases and ageing)
09.40	The Birth of Orphanet Identifying the Rare Disease information problem to implementing the solution
	<i>Personal accounts by the first players involved</i> Prof Jean-François Girard (Director, Directorate of Health from 1986 to 1997), Prof Claude Griscelli (Director of INSERM from 1996 to 2001), Etienne Caniard (Haute Autorité de Santé, Commission for quality and medical information), Prof Antoine Flahault (INSERM U707), Annie Wolf (Working group for orphan drugs)
10.00	Orphanet over the years
	<i>Orphanet's evolution in response to the evolution of needs</i> Dr Ségolène Aymé (Orphanet Director)
10.30	Orphanet as part of the French and international landscape
	<i>Panel discussion</i> Denise Silber (American medical Internet specialist consultant), Marie-Françoise de Pange (Quotidien du médecin), Prof Stefan Darmoni (CISMEF, University of Rouen), Prof Albert-Claude Benhamou (Francophone Virtual University)
11.00	Coffee break
11.30	Orphanet's service to the patients
	<i>Presentation of Orphanet services for patients and support groups</i> Marc Hanauer (Orphanet)
	<i>Partners and User representatives panel discussion</i> Laurence Tiennot Herment (Association Française contre les Myopathies), Françoise Antonini (Alliance Maladies Rares), Olivia Niclas (Fédération des Maladies Orphelines), Marie-Claude Bergmann (Maladies Rares Info Services),
12.15	Orphanet's service to Patients' and Professionals' Information
	<i>Presentation of Orphanet's services</i> Prof Didier Houssin, Director, Directorate of Health

12.25	<p>Orphanet's service to health professionals</p> <p><i>Presentation of Orphanet's services</i> Dr Ana Rath (Orphanet)</p> <p><i>Partners and User representatives panel discussion</i> Dr Marie-Claude Hittinger (Haute Autorité de Santé), Dr Christophe Leroy (Société Française de Médecine d'Urgence), Dr Lydia Valdès (Directorate of Health, Office for chronic diseases and ageing), Prof Didier Lacombe (Centre of reference for genetic embryonic development anomalies)</p>
13.00	<p>Lunch</p>
14.00	<p>Orphanet's service to Research</p> <p><i>Orphanet and its place within INSERM</i> Prof Christian Bréchet (Director of INSERM)</p> <p><i>Presentation of Orphanet's services</i> Valérie Thibaudeau (Orphanet)</p> <p><i>Partners and users panel discussion</i> Dr François Cartault (CHD Félix Guyon – Reunion Island), Prof Elisabeth Tournier-Lasserre (GIS - Institut des Maladies Rares), Dr Juliette Bloch (Institut de Veille Sanitaire), Dr Martine Lemerrer (Centre of reference for constitutional bone diseases - Genatlas), Dr John Mac Gregor (INSERM)</p>
15.00	<p>Orphanet's service to the development of Health products</p> <p><i>Presentation of Orphanet's services</i> Annick Dubosq (Orphanet)</p> <p><i>Partners and users panel discussion</i> Dr Chantal Belorgey (AFSSAPS), Dr Yves Juillet (LEEM), Dr Bernard Dauvergne (ADDMEDICA), Yann Le Cam (EURORDIS).</p>
15.45	<p>Orphanet's service to Europe and European citizens</p> <p><i>Presentation of the European Dimension</i> John Ryan (European Commission, Directorate Public Health and Risk Assessment)</p> <p><i>European partners panel discussion</i> Prof Mircea Covic (Romania), Dr Lina Florentin (Greece), Dr Loredana d'Amato-Sizonenko (Switzerland), Dr Margarida Reis Lima (Portugal), Prof Jean-Jacques Cassiman (Belgium)</p> <p>Video presentation from Marlene Haffner (FDA, Office of Orphan Product Development)</p>
16h30	<p>Conclusion by the French Health Minister, Xavier Bertrand</p>