

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	<p>Conference opens</p> <p><i>Public Health Stakes for Rare Diseases Information</i> Dr Carole Cretin (Directorate of Health, Office for chronic diseases and ageing)</p>
09.40	<p>The Birth of Orphanet Identifying the Rare Disease information problem to implementing the solution</p> <p><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), Dr Etienne Caniard (Haute Autorité de Santé, Commission for quality and medical information), Prof Antoine Flahault (INSERM U707)</p>
10.00	<p>Orphanet over the years</p> <p><i>Orphane's evolution in reply to the evolution of needs</i> Dr Ségolène Aymé (Orphanet Director)</p>
10.30	<p>Orphanet as part of the French and international landscape</p> <p><i>Panel discussion</i> Denise Silber (American medical Internet specialist consultant), Dr Stephan Darmoni (CISMEF, University of Rouen), Michèle Thonnet (French Ministry of Health, Working group for e-health systems), Prof Albert-Claude Benhamou (Francophone Virtual University)</p>
11.00	Coffee break
11.30	<p>Orphanet's service to the patients</p> <p><i>Presentation of Orphanet services for patients and support groups</i> Marc Hanauer (Orphanet)</p> <p><i>Partners and User representatives panel discussion</i> Françoise Antonini (Alliance Maladies Rares), Olivia Niclas (Fédération des Maladies Orphelines), Marie-Claude Bergman (Maladies Rares Info Services), Laurence Tiennot Herment (Association Française contre les Myopathies)</p>
12.15	<p>Orphanet's service to Patients' and Professionals' Information</p> <p><i>Presentation of Orphanet's services</i> Prof Didier Houssin, Director, Directorate of Health</p>

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 Lydia Valdès (Directorate of Health, Office for chronic diseases and ageing), Prof Didier Lacombe (Centre of reference for genetic embryonic development anomalies), Pr Loïc Guillevin (Centre of reference for necrotizing vasculitis and systemic scleroderma), Dr Christophe Leroy (Société Française de Médecine d'Urgence), Marie-Françoise de Pange (Quotidien du médecin), Dr Marie-Claude Hittinger (Haute Autorité de Santé)</p>
13.00	Lunch
14.00	<p>Orphanet's service to Research</p> <p><i>Presentation of Orphanet's services</i> Valérie Thibaudeau (Orphanet)</p> <p><i>Orphanet and its place within INSERM</i> Prof Christian Bréchet (Director of INSERM)</p> <p><i>Partners and users panel discussion</i> Prof Elisabeth Tournier-Lasserre (GIS - Institut des Maladies Rares), Dr Martine Lemerrer (Centre of reference for constitutional bone diseases - Genatlas), Dr Juliette Bloch (Institut de Veille Sanitaire), Dr John Mac Gregor (INSERM), Dr Françoise Cartault (CHD Félix Guyon – Reunion Island)</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> Andrzej Rys (Director of the European Commission, Directorate Public Health and Risk Assessment) <i>(to be confirmed)</i></p> <p><i>European partners panel discussion</i> Prof Jean-Jacques Cassiman (Belgium), Dr Loredana d'Amato-Sizonenko (Switzerland), Dr Margarida Reis Lima (Portugal), Dr Lina Florentin (Greece), Prof Mircea Covic (Romania)</p>
16h30	Conclusion by the French Health Minister, Xavier Bertrand
Birthday Buffet	