

22nd Workshop

EURORDIS Round Table of Companies (ERTC)

“ Rare Diseases: Going Global! ”

Wednesday 25 February, 2015 (9:30 to 16:30) - Le Plaza Hotel Brussels, Belgium

AGENDA

<p>Morning session co-chaired by:</p> <p>Prof. Kerstin Westermak - COMP, EMA; Medical Products Agency Sweden</p> <p>and Mr. Terkel Andersen – President, EURORDIS Board of Directors</p>	
9:30 – 9:45	Welcome address: Yann Le Cam (Chief Executive Officer, EURORDIS)
9:45 – 12:45	<i>International Strategies for Rare Diseases</i>
9:45 – 10:15	<p>Rare Disease International</p> <p>Durhane Wong-Rieger, PhD., President of the Canadian Organization for Rare Disorders (CORD)</p> <p><i>The new network of umbrella patient advocacy & support groups around the world to expand the rare disease movement and the global voice of rare disease patients</i></p>
10:15 – 10:45	<p>International Rare Diseases Research Consortium (IRDiRC)</p> <p>Paul Lasko, PhD., Chair of IRDiRC – presented by Yann Le Cam, EURORDIS</p> <p><i>The consortium of public funding bodies, regulatory agencies, industry and patient advocacy groups, to team up researchers and organisations investing in rare disease research in order to achieve the main objectives by year 2020 to deliver 200 new therapies for rare diseases and means to diagnose most rare diseases.</i></p>
10:45 – 11:15	<i>Coffee break</i>
11:15 – 11:45	<p>International Classification of Rare Diseases</p> <p>Annie Olry, PhD., Scientific Lead , Orphanet - Inserm US14</p> <p><i>The development, adoption and use of international classification (s) of rare diseases has grown significantly over the last years and will continue to be an active file in coming years: State-of-play of the Orpha code, ICD11, SNOMED CT</i></p>
11:45 – 12:45	<p>Panel discussion with all morning speakers and chairpersons:</p> <p>Why go global? What are the challenges? Where could we be in 2020?</p>
12:45 – 13:45	LUNCH

Afternoon session chaired by:

Dr. Marlene E. Haffner - CEO Haffner Associates, LLC
and Ms Claudia Hirawat - Chair, EURORDIS International Circle of Ambassadors

13:45 – 14:45	<i>Global R & D and local Regulations & Markets</i>
	<p>Panel discussion with CEOs or leaders of pharmaceutical companies, as well as regulators:</p> <ul style="list-style-type: none"> - How is industry embracing and leading in the globalisation? - What are the risks and opportunities? - What is needed for a better environment for rare disease therapy development? <p>Susanne Schaffert, Head Region Europe, Novartis Oncology Kristina Larsson, Head of Orphan Medicines, EMA Emmanuel Chantelot, Head of International Government Relations & Public Affairs, Shire Paul Ledger, Director Rare Disease Unit, GlaxoSmithKline Owen Marks, Senior Director and Team Leader for Pfizer Haemophilia</p>
14:45 – 16:30	<i>International Initiatives to Raise Awareness</i>
14:45 – 15:05	<p>Rare Disease Day Avril Daly, Vice President, Board of Directors, EURORDIS <i>The patient advocacy group annual campaign to raise public awareness, to engage policy makers and create a sense of global cross-over rare diseases multistakeholder community</i></p>
15:05 – 15:25	<p>RareConnect Denis Costello, RareConnect Leader, EURORDIS <i>The platform connecting rare disease patients globally and promoting multilingual conversations between them. Over 500 patient advocacy groups and over 200 volunteers are already forming 70 global rare disease communities. RareConnect's ambition for the years to come.</i></p>
15:25 – 15:45	<p>Orphanet beyond Europe Charlotte Gueydan, PhD., Quality Manager, Orphanet - Inserm US14 <i>The Orphanet website has long been consulted all around the world but now Orphanet is expanding in major countries beyond Europe, syndicating its services, to collect local information on resources (research programmes, centres of care, experts, medicines available) and to provide its services in more languages</i></p>

15:45 – 16:05	International Conference on Rare Diseases and Orphan Drugs (ICORD) John Forman, President of ICORD – presented by Dr. Marlene E. Haffner, CEO Haffner Associates, LLC <i>A vehicle to catalyse stakeholders and raise policy awareness in countries opening to rare diseases such as Argentina, Mexico, Japan.</i>
16:05 – 16:30	Q & A - Conclusions
16:30	Meeting ends