



## 21<sup>st</sup> Workshop

### EURORDIS Round Table of Companies (ERTC)

#### "Sharing Rare Disease Patient Data: Translating Principles into Action"

Tuesday 30 September, 2014 (9:00 to 16:00) - UAB - Casa Convalescència, Barcelona, Spain

#### AGENDA

<p>Morning session chaired by:  <b>Dr. Richard Bergström</b>          (European Federation of Pharmaceutical Industries and Associations)          and  <b>Prof. Bruno Sepodes</b>          (Committee for Orphan Medicinal Products (COMP), European Medicines Agency)</p>	
9:00 – 9:20	<b>Welcome address:</b> Yann Le Cam (Chief Executive Officer, EURORDIS)
9:20 – 12:30	<i>Morning Session: State-of-the-Art</i>
9:20 – 9:40	Results of the EPIRARE patient survey and Patient Advisory Council for RD-Connect: Anna Kole, EURORDIS
9:40 – 10:10	Ten Key Principles for Rare Disease Registries & Scenarios on Governance of a European Platform & EUCERD Recommendations: Yann Le Cam, EURORDIS
10:10 – 10:40	New Legal Environment for Data Protection: Alexander Denoon, Lawford Davies Denoon
10:40 – 11:10	Coffee break
11:10 – 11:40	Presentation of the JRC Platform (European Platform for Rare Disease Registries): Ciarán Nicholl, European Commission, DG Joint Research Centre – presented by Simona Martin
11:40 – 12:10	Experience of Data Sharing in RD-Connect: Hanns Lochmüller, Newcastle University
12:10 – 12:40	<b>Panel discussion</b> with Flaminia Macchia (EURORDIS), Richard Bergström (EFPIA), Francis Arickx (RIZIV/INAMI) and morning speakers
12:40 – 14:00	LUNCH
<p>Afternoon session chaired by:  <b>Mr. Guy Van den Eede</b>          (European Commission, Directorate-General Joint Research Centre (JRC))          and  <b>Ms. Sigurlaug Hauksdottir</b>          (European Commission, DG SANCO C2 - (Health Information))</p>	
14:00 – 16:00	<i>Afternoon Session: Public/Private Partnerships</i>
14:00 – 15:10	<p><i>Each group is assigned a room, a leader &amp; rapporteur</i></p> <p><b>Parallel breakout sessions:</b> (1h10' - including preparation of a short report)</p> <p><b>Topic 1:</b> Collaboration between industry &amp; the JRC Platform on rare disease registries</p> <p><b>Topic 2:</b> Collaboration of industry on rare disease registries managed by Centers of Expertise &amp; European Reference Networks</p> <p><b>Topic 3:</b> Data sharing &amp; commercialisation of data between industry and research infrastructures (RD-Connect/Innorate)</p>
15:10 – 15:40	<b>Plenary :</b> Feedback from each breakout session
15:40 – 16:00	<b>Panel discussion</b> with leaders of OMP Companies (Drs. Yamo Deniz, Genzyme, and Henrik Finnern, Boehringer Ingelheim) & Wrap up
16:00	Meeting ends