



27th Workshop of the EURORDIS Round Table of Companies (ERTC)

Patient engagement in the product life-cycle and community advisory boards (CABs)

Tuesday, 16 October 2018 (09:00 to 17:00)
Recinte Modernista – Barcelona - Spain

PRELIMINARY PROGRAMME

<p>Morning Session Chaired by: Co-chairs to be named</p>	
<p><i>Engaging with patients: from ticking a box to real value for business and patients</i></p>	
09:00 – 09:15	<p>Welcome introduction, setting the scene & goals for the day</p> <ul style="list-style-type: none"> • Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe
09:15 – 10:15	<p>Introducing the concept of patient engagement</p>
10:15 – 11:00	<p>Patient engagement with industry: needs and expectations</p> <ul style="list-style-type: none"> • The PARADIGM project: objectives and outcomes • Case study: joint development between a pharma company and a patient organisation
11 :00 – 11 :20	<p><i>Coffee break</i></p>
11 :20 – 12 :45	<p>Community Advisory Boards (CABs)</p> <p>Introduction & historical perspective – The Patient Investigator</p> <ul style="list-style-type: none"> • Rob Camp, Patient Engagement Senior Manager - CABs, EURORDIS <p>The EURO-CAB programme</p> <ul style="list-style-type: none"> • François Houÿez, Treatment Information and Access Director / Health Policy Advisor, EURORDIS <i>How to join a CAB, practical aspects, financial arrangements</i> <p>Interactive session with voting and Q&A</p>
12:45– 13:45	<p><i>Lunch</i></p>

Afternoon Session Chaired by:

François Houÿez, EURORDIS

Co-chairs to be named

From Concept to Reality

13:45 – 14:30	Case studies: recent CABs (active or in creation)
14:30 – 14:40	Introduction to the breakout sessions Afternoon co-chairs
14:45 – 15:55	Breakout session 1: difficulties, challenges, special considerations Situation 1: The sponsor is a not-for-profit, small biotech, or start-up pharmaceutical company
	Breakout session 2: difficulties, challenges, special considerations Situation 2: The sponsor or the co-sponsor is a patient organisation or a joint venture with a patient organisation
	Breakout session 3: difficulties, challenges, special considerations Situation 3: The sponsor is a large pharmaceutical company
16:00 – 16:20	Feedback from breakout sessions Moderated by afternoon co-chairs
16:20 – 16:45	Questions to key actors
16:45 – 17:00	Concluding remarks
17:00	<i>Meeting ends</i>