



## 28th Workshop of the EURORDIS Round Table of Companies (ERTC)

### A New PARADIGM of Meaningful Patient Engagement in the Life Cycle of Medicines

Tuesday, 15 October 2019 (09:00 to 17:00) Hospital Sant  
Pau Recinte Modernista – Barcelona - Spain

### PROGRAMME

<p><b>Morning Session Co-Chaired by:</b></p> <p><b>Dr Stuart Faulkner</b>, Programme and Operations Manager, Oxford University  <b>Dr Virginie Hivert</b>, Therapeutic Development Director, EURORDIS-Rare Diseases Europe</p>	
<p><b>Tools for Meaningful and Ethical Patient Engagement</b></p>	
09:00 – 09:15	<p><b>Welcome introduction, setting the scene &amp; goals for the day</b>  <b>Yann Le Cam</b>, Chief Executive Officer, EURORDIS-Rare Diseases Europe</p>
09:15 – 09:30	<p><b>Patient Engagement at EURORDIS: capacity, capability and tools</b>  <b>Dr Elisa Ferrer</b>, Patient Engagement Senior Manager, EURORDIS-Rare Diseases Europe</p>
09:30 – 09:50	<p><b>2nd PARADIGM Conference: Learnings for rare diseases</b>  <b>Dr Vinciane Pirard</b>, Director Public Affairs, Sanofi – Genzyme</p>
09:50 – 10:10	<p><b>Patient Engagement: Benefits for Patients, Industry and Society</b>  <b>Alain Cornet</b>, General Secretary, Lupus Europe  <b>Grainne Crowley</b>, Head Patient Advocacy Europe and Canada, Biogen</p>
10:10 – 10:40	<p><b>Tools for Meaningful and Ethical Patient Engagement: Part I</b>  <b>Individual patients’ data</b>  <b>Nicholas Brooke</b>, Executive Director and Founder of The Synergist, Executive Director of Patient Focused Medicines Development (PFMD)  <b>Aggregated data: Developments from the rare disease patient community</b>  <b>Julian Isla</b>, Chairman, Dravet Foundation</p>
10 :40 – 11 :10	<p><i>Coffee break</i></p>
11 :10 – 11:40	<p><b>Tools for Meaningful and Ethical Patient Engagement: Part II</b></p> <p><b>Fair market value (FMV) &amp; Compensation of Patients</b>  <b>Hans Scheurer</b>, President, Myeloma Patients Europe</p> <p><b>Council for International Organisations of Medical Sciences (CIOMS) Working Group XI</b>  <b>François Houyez</b>, Treatment Information and Access Director, Health Policy Advisor, EURORDIS-Rare Diseases Europe</p>

11:40 – 12:25	<p><b>Panel Discussion</b></p> <p><b>Chair:</b> Dr Stuart Faulkner, Programme and Operations Manager, Centre for Advancement of Sustainable Medical Innovation</p> <p><b>Panellists:</b> selected speakers from morning session</p>
12:25 – 12:30	<p><b>Introduction to the breakout sessions</b></p> <p><b>Dr Virginie Hivert</b>, Therapeutic Development Director, EURORDIS-Rare Diseases Europe</p>
12:30– 13:45	<p><i>Lunch</i></p>
<p style="text-align: center;"><b>Afternoon Session Co-Chaired by:</b></p> <p style="text-align: center;"><b>Dr Maria Mavris</b>, Patient Relations, European Medicines Agency</p> <p style="text-align: center;"><b>Pooja Merchant</b>, Head, Patient Partnerships and Engagement Oncology Global Medical Affairs, Bayer Pharmaceuticals</p>	
<p style="text-align: center;"><b>Return on engagement, competing interests and legal considerations of Community Advisory Boards (CABs)</b></p>	
13:45 – 15:45	<p><b>Breakout session 1: Return on Engagement: Evaluation Tools and Monitoring for Collaborative Activities</b></p> <p>In this session we will address:</p> <ul style="list-style-type: none"> <li>✓ Development of a monitoring and evaluation framework: PARADIGM</li> <li>✓ XXX Metrics for success for patients and industry</li> <li>✓ How to apply the framework in your Patient Engagement activities</li> <li>✓ Test framework exercise</li> </ul> <ul style="list-style-type: none"> <li>• <b>Moderator:</b> Dr Paul Robinson, Executive Director, Patient Perspectives, Merck Sharp &amp; Dohme</li> <li>• <b>Rapporteur:</b> Dr Elisa Ferrer, Patient Engagement Senior Manager, EURORDIS-Rare Diseases Europe</li> </ul> <hr/> <p><b>Breakout session 2: Return on Engagement: Evaluation Tools and Monitoring for Community Advisory Boards (CABs)</b></p> <p>In this session we will address:</p> <ul style="list-style-type: none"> <li>✓ Development of a monitoring and evaluation framework: EURORDIS CAB</li> <li>✓ Metrics for success for patients and industry</li> <li>✓ How to apply the framework in your Patient Engagement activities</li> </ul> <ul style="list-style-type: none"> <li>• <b>Moderator:</b> Lidewij Vat, Researcher and Lecturer, Meaningful and Sustainable Patient Engagement, Athena Institute, Vrije Universiteit Amsterdam</li> <li>• <b>Rapporteur:</b> Rob Camp, Patient Engagement Senior Manager Community Advisory Board (CAB) Programme, EURORDIS-Rare Diseases Europe</li> </ul> <hr/> <p><b>Breakout session 3: Competing Interests in a Multi-Stakeholder Environment</b></p> <p>In this session we will address:</p> <ul style="list-style-type: none"> <li>✓ The Management of competing interests in a multi-stakeholder environment (Competing Interests, Declaration of interests, Assessment framework/policies, Conflicts of interests and mitigation measures)</li> <li>✓ Influence of confidentiality on Management of Competing Interests</li> <li>✓ Perception versus reality of conflicts of interests</li> <li>✓ Protection of the processes versus real barriers to patient engagement</li> </ul> <ul style="list-style-type: none"> <li>• <b>Moderator:</b> Dr Virginie Hivert, Therapeutic Development Director, EURORDIS- Rare Diseases Europe</li> <li>• <b>Rapporteur:</b> Walter Atzori, Director Alliance Development EMEA, Alexion Services Europe (Be)</li> </ul>

15:45 – 16:15	<i>Coffee break and return to plenary room</i>
16:15 – 16:40	<b>Feedback from breakout sessions</b> Moderated by afternoon co-chairs
16:40 – 16:50	<b>Applying Meaningful and Ethical Patient Engagement in Industry</b> <b>Emanuele Degortes</b> , Head of Patient, Innovation and Access Policy, Vifor Pharma Ltd.
16:50 – 17:00	<b>Concluding remarks</b> <b>Toolkit overview: next steps on how to implement what you have heard today</b> <b>Yann Le Cam</b> , EURORDIS-Rare Diseases Europe, Chief Executive Officer
17:00	<i>Meeting ends</i>