# 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

**Morning Session Co-Chaired by:**
- Dr Stuart Faulkner, Programme and Operations Manager, Oxford University
- Dr Virginie Hivert, Therapeutic Development Director, EURORDIS-Rare Diseases Europe

### Tools for Meaningful and Ethical Patient Engagement

<table>
<thead>
<tr>
<th>Time</th>
<th>Topic</th>
<th>Speakers</th>
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<tbody>
<tr>
<td>09:00 – 09:15</td>
<td>Welcome introduction, setting the scene &amp; goals for the day</td>
<td>Yann Le Cam, Chief Executive Officer, EURORDIS-Rare Diseases Europe</td>
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<tr>
<td>09:15 – 09:30</td>
<td>Patient Engagement at EURORDIS: capacity, capability and tools</td>
<td>Dr Elisa Ferrer, Patient Engagement Senior Manager, EURORDIS-Rare Diseases Europe</td>
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<td>09:30 – 09:50</td>
<td>2nd PARADIGM Conference: Learnings for rare diseases</td>
<td>Dr Vinciane Pirard, Director Public Affairs, Sanofi – Genzyme</td>
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<td>09:50 – 10:10</td>
<td>Patient Engagement: Benefits for Patients, Industry and Society</td>
<td>Alain Cornet, General Secretary, Lupus Europe</td>
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<td>Grainne Crowley, Head Patient Advocacy Europe and Canada, Biogen</td>
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<td>10:10 – 10:40</td>
<td>Tools for Meaningful and Ethical Patient Engagement: Part I</td>
<td>Nicholas Brooke, Executive Director and Founder of The Synergist, Executive Director of Patient Focused Medicines Development (PFMD)</td>
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<td>Aggregated data: Developments from the rare disease patient community</td>
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<td>Julian Isla, Chairman, Dravet Foundation</td>
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<td>10:40 – 11:10</td>
<td>Coffee break</td>
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<td>11:10 – 11:40</td>
<td>Tools for Meaningful and Ethical Patient Engagement: Part II</td>
<td>Fair market value (FMV) &amp; Compensation of Patients</td>
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<td>Hans Scheurer, President, Myeloma Patients Europe</td>
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<td>Council for International Organisations of Medical Sciences (CIOMS) Working Group XI</td>
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<td>François Houyéz, Treatment Information and Access Director, Health Policy Advisor, EURORDIS-Rare Diseases Europe</td>
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### Panel Discussion
**Chair:** Dr Stuart Faulkner, Programme and Operations Manager, Centre for Advancement of Sustainable Medical Innovation
**Panellists:** selected speakers from morning session

### Introduction to the breakout sessions
**Dr Virginie Hivert,** Therapeutic Development Director, EURORDIS-Rare Diseases Europe

### Lunch

**Afternoon Session Co-Chaired by:**
- Dr Maria Mavris, Patient Relations, European Medicines Agency
- Pooja Merchant, Head, Patient Partnerships and Engagement Oncology Global Medical Affairs, Bayer Pharmaceuticals

**Return on engagement, competing interests and legal considerations of Community Advisory Boards (CABs)**

### Breakout session 1: Return on Engagement: Evaluation Tools and Monitoring for Collaborative Activities

In this session we will address:
- Development of a monitoring and evaluation framework: PARADIGM
- XXX Metrics for success for patients and industry
- How to apply the framework in your Patient Engagement activities
- Test framework exercise
  - **Moderator:** Dr Paul Robinson, Executive Director, Patient Perspectives, Merck Sharp & Dohme
  - **Rapporteur:** Dr Elisa Ferrer, Patient Engagement Senior Manager, EURORDIS-Rare Diseases Europe

### Breakout session 2: Return on Engagement: Evaluation Tools and Monitoring for Community Advisory Boards (CABs)

In this session we will address:
- Development of a monitoring and evaluation framework: EURORDIS CAB
- Metrics for success for patients and industry
- How to apply the framework in your Patient Engagement activities
  - **Moderator:** Lidewij Vat, Researcher and Lecturer, Meaningful and Sustainable Patient Engagement, Athena Institute, Vrije Universiteit Amsterdam
  - **Rapporteur:** Rob Camp, Patient Engagement Senior Manager Community Advisory Board (CAB) Programme, EURORDIS-Rare Diseases Europe

### Breakout session 3: Competing Interests in a Multi-Stakeholder Environment

In this session we will address:
- The Management of competing interests in a multi-stakeholder environment (Competing Interests, Declaration of interests, Assessment framework/policies, Conflicts of interests and mitigation measures)
- Influence of confidentiality on Management of Competing Interests
- Perception versus reality of conflicts of interests
- Protection of the processes versus real barriers to patient engagement
  - **Moderator:** Dr Virginie Hivert, Therapeutic Development Director, EURORDIS- Rare Diseases Europe
  - **Rapporteur:** Walter Atzori, Director Alliance Development EMEA, Alexion Services Europe (Be)
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<th>Time</th>
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<tr>
<td>15:45 – 16:15</td>
<td>Coffee break and return to plenary room</td>
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| 16:15 – 16:40 | Feedback from breakout sessions  
Moderated by afternoon co-chairs                                      |
| 16:40 – 16:50 | Applying Meaningful and Ethical Patient Engagement in Industry  
Emanuele Degortes, Head of Patient, Innovation and Access Policy, Vifor Pharma Ltd. |
| 16:50 – 17:00 | Concluding remarks  
Toolkit overview: next steps on how to implement what you have heard today  
Yann Le Cam, EURORDIS-Rare Diseases Europe, Chief Executive Officer |
| 17:00 | Meeting ends |