11TH EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS

ONLINE

27 JUNE – 1 JULY 2022

MISSION IMPOSSIBLE
PUTTING RARE DISEASE POLICY INTO ACTION
ECRD Attendance
Programme Outline

**Monday**
14:00-18:00 CET

**Focus:** Overarching theme, Europe’s Action Plan, Planning policies, Cohesive strategy

**OPENING PLENARY**
Poster Winners Presentation, Orientation & Networking session

Thought leader sessions

**Tuesday**
14:00-18:00 CET

**Goal:** Ensuring healthy lives and promoting well-being for all people living with a rare disease at all age

2 x parallel sessions

2 x parallel sessions

**Wednesday**
14:00-18:00 CET

**Goal:** Reducing inequalities for people living with a rare disease

1 plenary session

+ 2 x parallel sessions

**Thursday**
14:00-18:00 CET

**Goal:** Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for people living with a rare disease

2 x parallel sessions

+ 2 x parallel sessions

**Friday**
14:00-17:00 CET

**Focus:** EU at large and international, how to contribute to SDGs, WHO Europe

Parallel Member State Zoom Meetings

Networking session

CLOSING PLENARY

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CLOSING PLENARY
Timeline
Working Proposal for Europe’s Action Plan for Rare Diseases

2021
- Portugal
- 23 Feb 2021: Rare 2030 Policy Conference
- 31 May 2021: Rare 2030 Final Recommendations

2022
- Slovenia
- 28 Feb 2022: EU Council French Presidency High Level Conference on RDs
- France
- July-Dec 2022: EU Council Presidency Technical Meetings

2023
- Czech Republic
- Feb 2023: EU Council Presidency Technical Meetings
- Sweden
- Feb 2023: Presentation of the EC Roadmap
- Spain
- Dec 2023: EC Adoption of Action Plan

June 2021 – November 2021: Launch of #30 million reasons campaign including formal contacts to EC President, Commissioners and DGs

April - Sept 2023: Consultations

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8 Rare 2030 Recommendations

1. European/national plans and strategies
2. Diagnosis
3. Access to care
4. Person-centred care
5. Patient Partnerships
6. Research
7. Data
8. AAA Treatments

3 Goals in Europe’s Action Plan

GOAL 1: Ensuring healthy lives and promoting well-being for all PLWRD

GOAL 2: Reducing inequalities for PLWRD

GOAL 3: Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for PLWRD

4 United Nations Sustainable Development Goals

SDG 3: Ensure healthy lives and promote well-being for all at all ages

SDG 9: Build resilient infrastructure, promote inclusive and sustainable industrialisation and foster innovation

SDG 10: Reduce inequalities within/among countries

SDG 17: Revitalise the global partnership for sustainable development

eurordis.org/30millionreasons
**Topics Addressed**

<table>
<thead>
<tr>
<th>Day</th>
<th>Time</th>
<th>Focus/Goal</th>
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<tbody>
<tr>
<td>Monday</td>
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**Monday**

**Focus:** Overarching theme, Europe’s Action Plan, Planning policies, Cohesive strategy

**Goals:**
- Ensuring healthy lives and promoting well-being for all people living with a rare disease at all age
- Reducing inequalities for people living with a rare disease
- Building resilient infrastructure, promoting inclusive and sustainable industry and fostering innovation for people living with a rare disease

**Friday**

**Focus:** EU at large and international, how to contribute to SDGs, WHO Europe

**Topics Addressed:**
- Diagnostic testing
- Screening technologies & early detection
- Evidence-based care and support for rare disease patients
- Highly specialised healthcare (European CoE lighthouses)
- Innovative Therapies
- Technical improvements:
  - De-risking product development
  - CBHC directive for CTs and funding mechanisms
- Fragmentation of the EU market
- Allocative improvements:
  - Distribution of resources for healthcare budgets
  - Benefit corporations
- Transversal topic: Data

European Reference Network (ERN) for Rare Diseases.
What is EURORDIS offering?

- Platform and technology to host a 90-minute multi-stakeholder discussion on key areas of your national plan (in your native language)
- Help to make your discussion politically relevant > template agenda
- Inclusion of your meeting as part of the official programme
- Note-taking template to capture your key messages
- Inclusion of your key messages in the Executive Summary
- Promotion of the meeting to all pre-registered participants of the conference
Breakdown by country:

Participants Vienna 2018

- UK: 18%
- France: 13%
- Austria: 12%
- Germany: 10%
- Netherlands: 8%
- Belgium: 8%
- Italy: 6%
- Switzerland: 7%
- USA: 6%

Participants Edinburgh 2016

- UK: 32%
- France: 16%
- Germany: 11%
- Netherlands: 9%
- Italy: 7%
- Belgium: 7%
- Switzerland: 6%
- USA: 5%
- Sweden: 4%

Participants Online 2020

- UK: 18%
- Sweden: 12%
- France: 11%
- Germany: 11%
- Netherlands: 10%
- Belgium: 9%
- Italy: 8%
- Switzerland: 8%
- USA: 7%

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Overall Top 10:

<table>
<thead>
<tr>
<th>Country</th>
<th>Participants On Average</th>
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<tbody>
<tr>
<td>United Kingdom</td>
<td>158</td>
</tr>
<tr>
<td>France</td>
<td>98</td>
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<tr>
<td>Austria</td>
<td>86</td>
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Breakdown by stakeholder group

- Patient representatives: 15%
- ERN/Academics/Healthcare Professionals: 9%
- Healthcare Industry: 3%
- Payer bodies/HTA agencies/Regulators/Policy Makers: 1%
- Medical Students: 20%
- Press: 52%
What can you do as a National Alliance?

- Invite your national authority representative(s) and/or your national plan committee members
- Co-create the meeting agenda with your national plan committee members
- Moderate the conversation:
  - Discuss ways to push forward the key areas of your national plan
  - Focus on solutions and commitments to implement some of these policies
- Take notes using the template to be provided by EURORDIS
- Send your notes to EURORDIS for inclusion in the ECRD 2022 Executive Summary
- Request interviews with EURORDIS board, staff, VIP speakers or other invited speakers
What benefits are there for you?

- Increased visibility
- EU context & official labelling
- Follow-up opportunity / check-in after Rare Disease Day
- Prepare for integration of EU policy at national level & vice versa
- Platform and ready-made multi-stakeholder audience
- Another opportunity to grab the attention of your national authorities
- Inclusion in ECRD 2022 Executive Summary
- Potential increased media exposure
How can we help you?
More information

If you are interested in taking advantage of this opportunity, contact

sharon.ashton@eurordis.org