12th European Conference on Rare Diseases & Orphan Products
15 & 16 May 2024
What is the ECRD?

A policy-shaping event, an instrumental tool to achieve our policy objectives for people living with a rare disease

Harnesses the power of our extensive network of partners, stakeholders and participants: patient advocates, researchers, healthcare professionals, health care corporates and policymakers, to activate and drive positive change

Takes stock of the current state of rare disease-related work, monitors and tracks progress and provides a unique forum to share experiences, and to exchange ideas/network

This collective effort allows us to distil these discussions into clear policy recommendations and better advocate for change

The next ECRD will take place as a fully hybrid conference on 15-16 May 2024, at The Square in Brussels and online!
ECRD 2024 overarching objectives

- Footprint for next legislative cycle
- Bottom-up approach
- RDs at the forefront of healthcare innovation
ECRD 2024 Topics Addressed

- European and national policies /strategies/plans
- Access, availability and affordability of treatments
- Diagnosis and screening
- Research and innovation
- Mental wellbeing and holistic care
- Access to highly specialised care
Satellite Meetings: what’s in it for you?

• Increased visibility
• EU context & official ECRD 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 2024 Executive Summary
• Potential increased media exposure
It was a big plus that we could do the workshop under the logo of ECRD and as a part of the official program. The workshop was the platform of bringing together important stakeholders in order to re-vitalise our National Strategy with great success. The NBH announced during the workshop, that an external evaluation of the Strategy is on its way. And it is!! It is to be concluded before new year THIS year [2022]. We would welcome other opportunities to conduct national activities as a part of European conferences and other gatherings.

Lene Jensen

Director, Rare Diseases Denmark
ECRD 2022 registrants

- Patients: 49%
- Healthcare Professionals/Academics/ERNs: 20%
- Industry: 13%
- Payers/Policy/HTA: 13%
- Students: 3%
- Press: 2%
What is EURORDIS offering?

- NA Satellite Meeting listing in the official ECRD 2024 programme.
- Promotion of your satellite meeting to all pre-registered participants.
- Support to help shape the narrative and scope of the satellite meeting.
- Note-taking template to capture your key messages / national priorities
- Possibility for your MoH, MEP candidate or other key national representative speaking in your Satellite Meeting to pre-record a video message to feed into the main conference.

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What can you do as a National Alliance?

- Use the ECRD 2024 official branding for announcements and invitations.
- Co-create the meeting agenda with your national plan committee members.
- Moderate the conversation.
- Take notes using the template provided by EURORDIS.
- Send notes to EURORDIS for inclusion in the ECRD 2024 Executive Summary.
- Request interviews with EURORDIS board, staff, VIP speakers or other invited speakers.
Any questions?
Next steps

Rachel will share these slides with you!

And is available to answer questions and provide more information: rachel.butcher@eurordis.org
Current Political landscape

RD Policy Framework

Research Policy & Activities
- Rare Diseases Partnership

Data & Digital Health
- European Health Data Space

Development & Access to Diagnostic & Therapies
- Pharma legislation
- Substance of Human origin
- HTA implement
- Early diagnosis

Healthcare Policy & Services
- Evolution of the ERNs
- Mental wellbeing

Social Policy & Services
- Disability assessment & Disability Card
Proposal from the RD Community & Rare 2030 for a European policy framework: A European Action Plan / Strategy on Rare Diseases

8 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. Available, Accessible and Affordable Treatments

A Goals-based Strategy

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

Linked to 4 SDGs

SDG3: 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

SDG10: Reduce inequalities within/among countries

SDG17: Revitalise the global partnership for sustainable development
Draft Programme Outline

**OPENING PLENARY**
- Facilitated networking
- Posters Pitch
- Parallel sessions
- Community-led discussions
- Daily news round up
- Networking reception

**Wednesday**
15th May 2024

**Thursday**
16th May 2024
- Surprise speaker
- Posters Pitch & Awards
- Parallel sessions x 2
- Daily news round up
- CLOSING PLENARY