ecrd

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!**

Timeline

29 February
RDD 2024

6-9 June
EP Elections

October (?)
Rare Disease
Week

15-16 May
ECRD 2024

July 2023 | - | Dec 2023 | Jan 2024 | - | June 2024 | July 2024 | - | Dec 2024

SPAIN

BELGIUM

HUNGARY

Presidencies

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
- Research and innovation
- Access, availability and affordability of treatments
- Mental wellbeing and holistic care
- Diagnosis and screening
- Access to highly specialised care

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Satellite Meetings: what's in it for you?

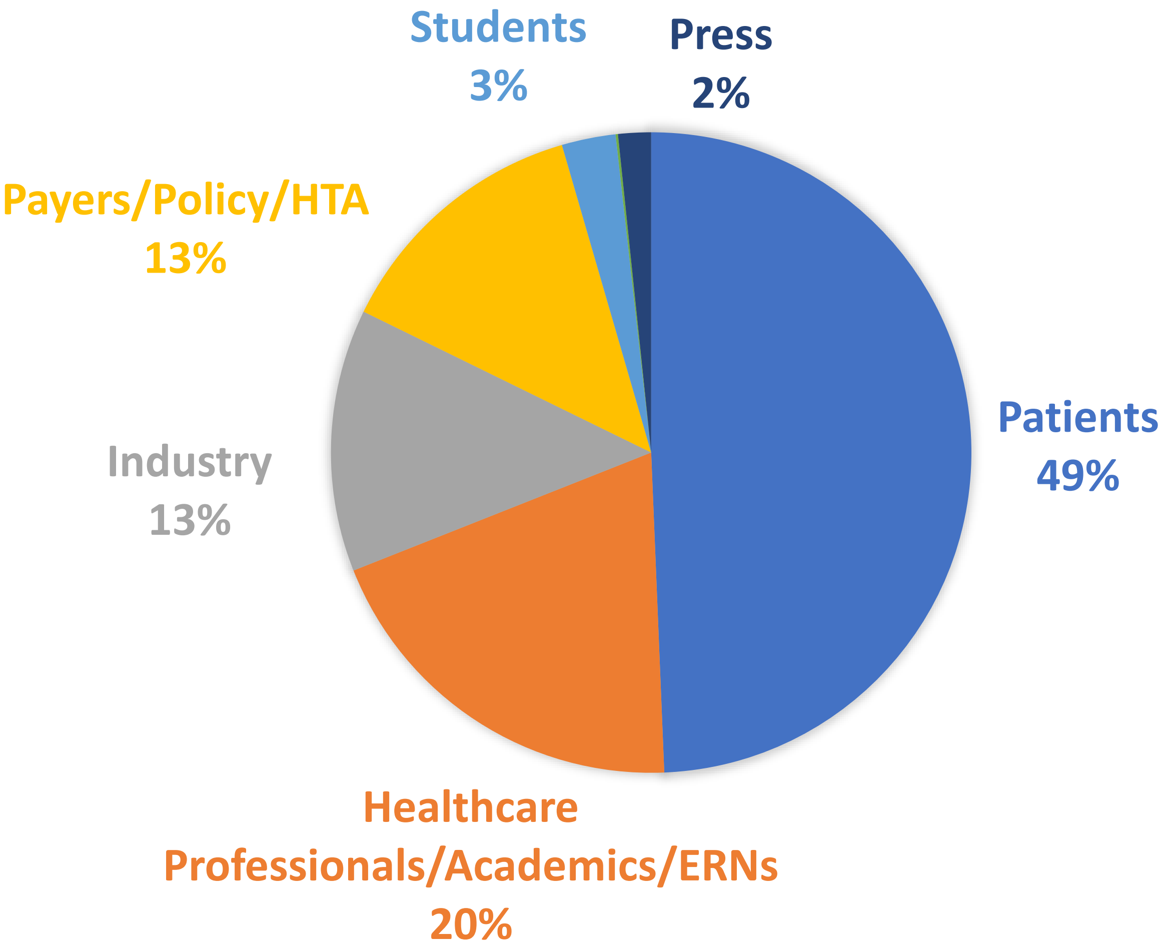
- Increased visibility
- EU context & official ECRD labelling
- Follow-up opportunity / check-in after Rare Disease Day
- Prepare for integration of EU policy at national level & vice versa
- Platform and ready-made multi-stakeholder audience
- Another opportunity to grab the attention of your national 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

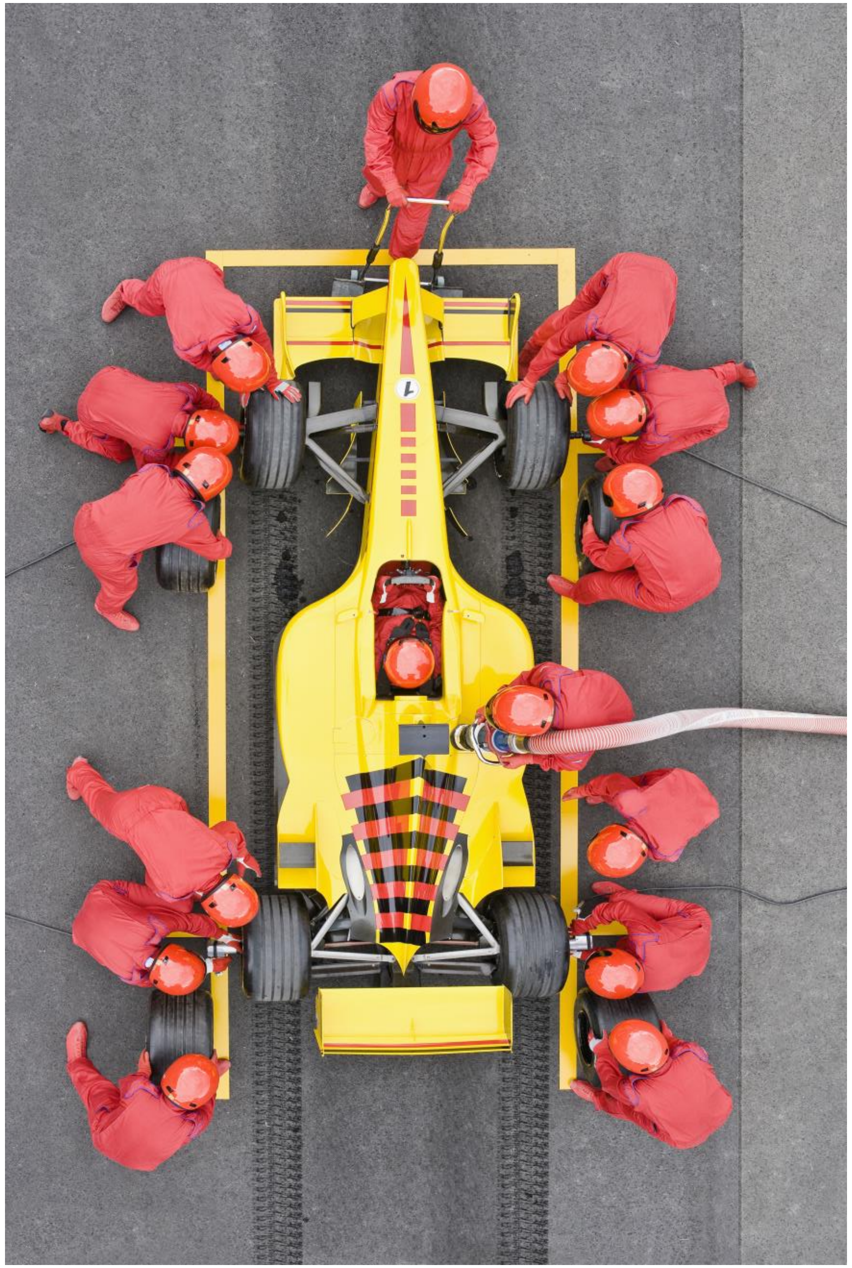
Director, Rare Diseases Denmark

ECRD 2022 registrants



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.



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.

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Any questions?


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MISSION POSSIBLE
PUTTING RARE DISEASE POLICY INTO ACTION


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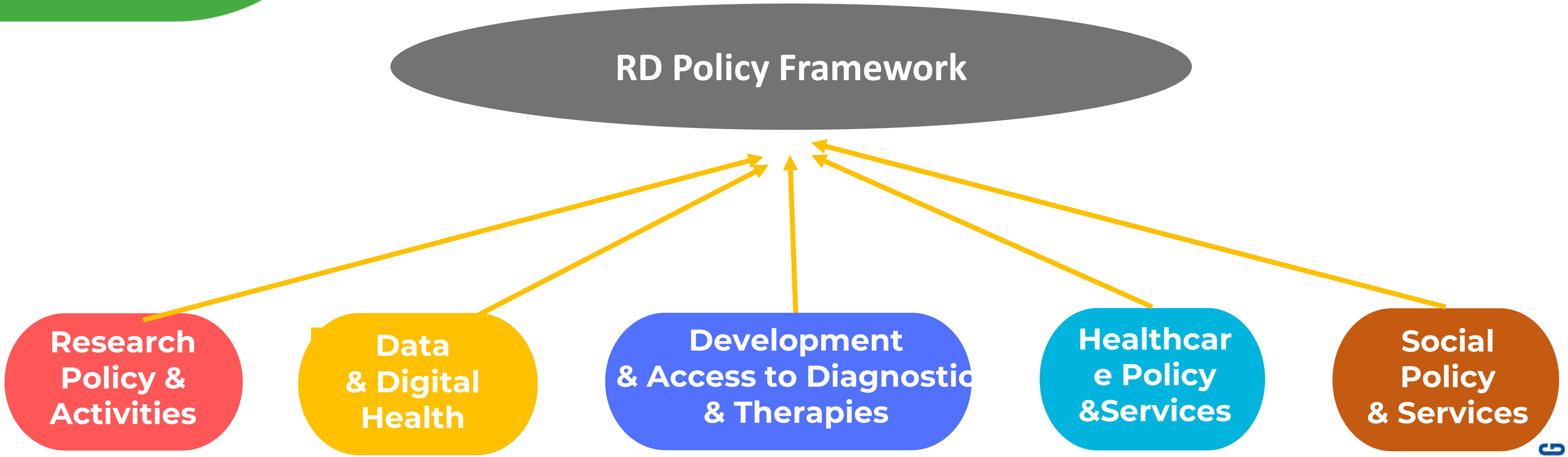
Next steps

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

Wednesday 15th May 2024	**Thursday** 16th May 2024
OPENINIG PLENARY	
Facilitated networking	Surprise speaker
Posters Pitch	Posters Pitch & Awards
Parallel sessions	Parallel sessions x 2
Community-led discussions	Daily news round up
Daily news round up	CLOSING PLENARY
Networking reception	