

# EURORDIS MEMBERSHIP MEETING

22 - 24 MAY

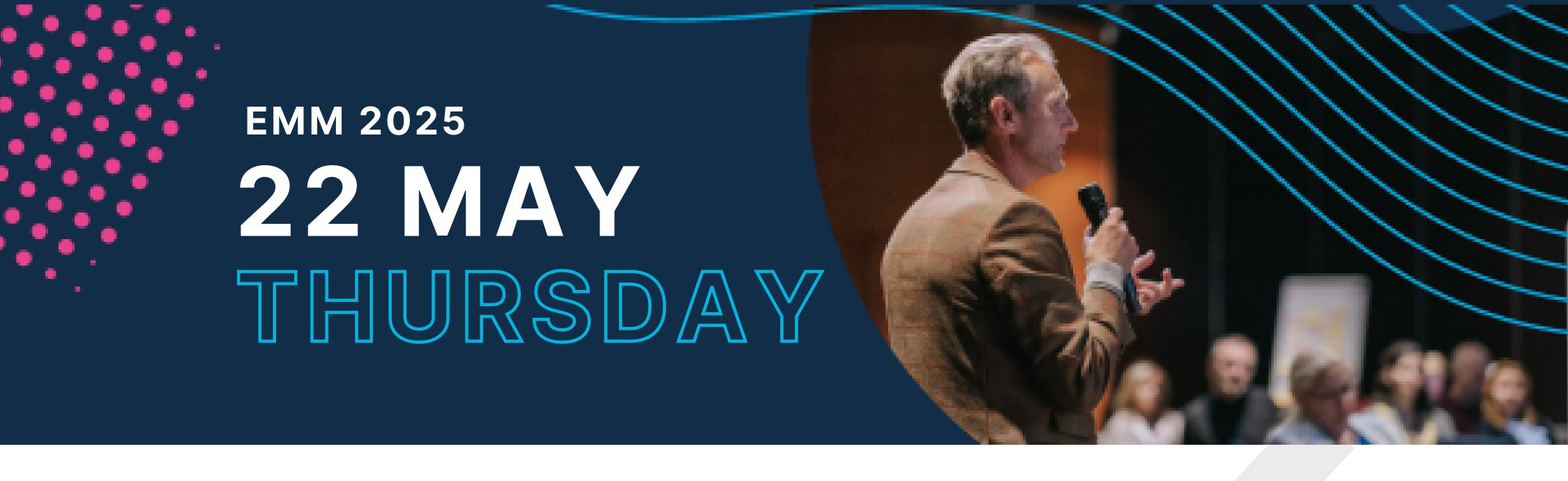
# ] ##EMM2025

RIGA, LATVIA RADISSON BLU LATVIJA CONFERENCE & SPA HOTEL



For more information, please contact:

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# 11.00 18.00

## **Meeting of the Council of National Alliances**

This is a closed-door meeting bringing together representatives from national alliances to discuss internal coordination, strategic priorities, and upcoming joint initiatives.

14.00 18.00

### **Mental Health Workshop**

Moderator: Matt Bolz-Johnson, EURORDIS

This workshop aims to develop the capacities of patient group leads by sharing tools and approaches that have worked for other communities in addressing the mental health impact and challenges associated with a rare disease journey.

Through facilitated peer-training exercises and discussion, we want to support your community to be resilient in terms of mental health and wellbeing; as well as explore approaches that help patient advocates and leaders to look after themselves when supporting others, specifically on how to avoid burnout and why work-life balance can be difficult.

- Kirsten Johnson, Fragile X International, UK
- Kym Winter, Rare Minds, UK
- Ben Sears, Rare Minds, UK
- Lauren Roberts, Rare Minds, UK

# 9.3011.00

### **EMM Plenary**

### **Moderator:**

Johan de Graaf, Nederlandse Hypofyse Stichting, Netherlands Caroline van den Bosch, Hevas, Netherlands

Welcome speech, Virginie Bros-Facer, CEO, EURORDIS

Opening speech, Hosams Abu Meri, Minister for Health of the Republic of Latvia

Speaking with one voice, Avril Daly, President, EURORDIS

#### **Panel discussion:**

- How can we speak with one voice at a local/national/international level?
- What have we achieved already?
- What is the impact of advocacy at a global level?

#### **Panellists:**

- Marta Augucēviča, Latvian Alliance for Rare Diseases
- Daniel de Vicente, FEDER, Spain
- Nick Meade, Genetic Alliance UK

11.0011.20

Break

11.2011.40

# Building advocacy strategies based on Rare Barometer survey results

Jessie Dubief, Social Research Director & Rare Barometer Programme Lead, EURORDIS-Rare Diseases Europe



# 11.4012.10

## Presentation of the Patient Partnership Framework for the ERNs

Ines Hernando, ERN and Healthcare Director, EURORDIS-Rare Diseases Europe

# 12.10 12.30

## Introduction to patient engagement across the medicines' lifecycle

Maria Cavaller, Patient Engagement & Therapeutic Development Director, Julien Delaye, Patient Engagement Manager - HTA, EURORDIS-Rare Diseases Europe

# 12.3014.00

#### Lunch

# 14.0017.30

## Workshops

Three workshops will take place in parallel. Participants are invited to attend one of the following:

- Engaging with policymakers at a national and European level (also offered on Saturday)
- Volunteer engagement across the medicine's lifecycle and in healthcare (part 1)
- Using Rare Barometer results for advocacy (also offered on Saturday)

Full workshop descriptions are available on page 8.

09.0012.30

### Workshops

Three workshops will take place in parallel. Participants are invited to attend one of the following:

- Engaging with policymakers at a national and European level (repeat of Friday)
- Volunteer engagement across the medicine's lifecycle and in healthcare (part 2)
- Using Rare Barometer results for advocacy (repeat of Friday)

Full workshop descriptions are available on page 8.

12.3014.00

Lunch



Workshop: "Engaging with policymakers at a national and European level"

Moderators: Raquel Castro, Valentina Bottarelli, EURORDIS

This session will guide members through strategies, resources, and practical exercises to help them advocate effectively for improved access to healthcare, treatments, and support for individuals with rare diseases and their families.

It is designed to introduce members to a basic advocacy toolkit that can be used to engage with policymakers at both European and national levels, ensuring that the voices and needs of people living with rare diseases are heard and addressed in policy discussions.

The accompanying toolkit will be shared in advance. It is structured to help advocates understand the advocacy process, build relationships with key policymakers, and develop impactful advocacy campaigns.

- Raquel Castro, EURORDIS
- Valentina Bottarelli, EURORDIS
- Antoni Montserrat, ALAN, Luxembourg
- Adrian Goretzki, Healthcare Education Institute, Poland



# Workshop: "Volunteer engagement across the medicine's lifecycle and healthcare" (Part 1)

Moderators: Maria Cavaller, Ines Hernando, EURORDIS

This session will explore how patient representatives can engage with the European Medicines Agency (EMA), European Reference Networks (ERNs), and Health Technology Assessment (HTA) bodies. It will explain the role patient representatives play in these organisations and their impact on decision-making.

We will also cover practical information, including time commitments, required skills, and different engagement policies.

Through presentations, interactive table discussions with experienced volunteers, and a Q&A session, participants will gain a comprehensive understanding of engagement pathways, helping them make informed decisions about their potential involvement in the medicines development process.

### **Facilitators:**

- Ines Alves, Associação Nacional De Displasias Ósseas, Portugal
- Maria Cavaller, EURORDIS
- Flavia Galletti, Associazione Italiana Rene Policistico, Italy
- Tomasz Grybek, Foundation of Borys the Hero, Poland
- David Sanchez, Asociación Retina Murcia, Spain
- Dr Frank Willersinn, Alpha-1 Europe Alliance



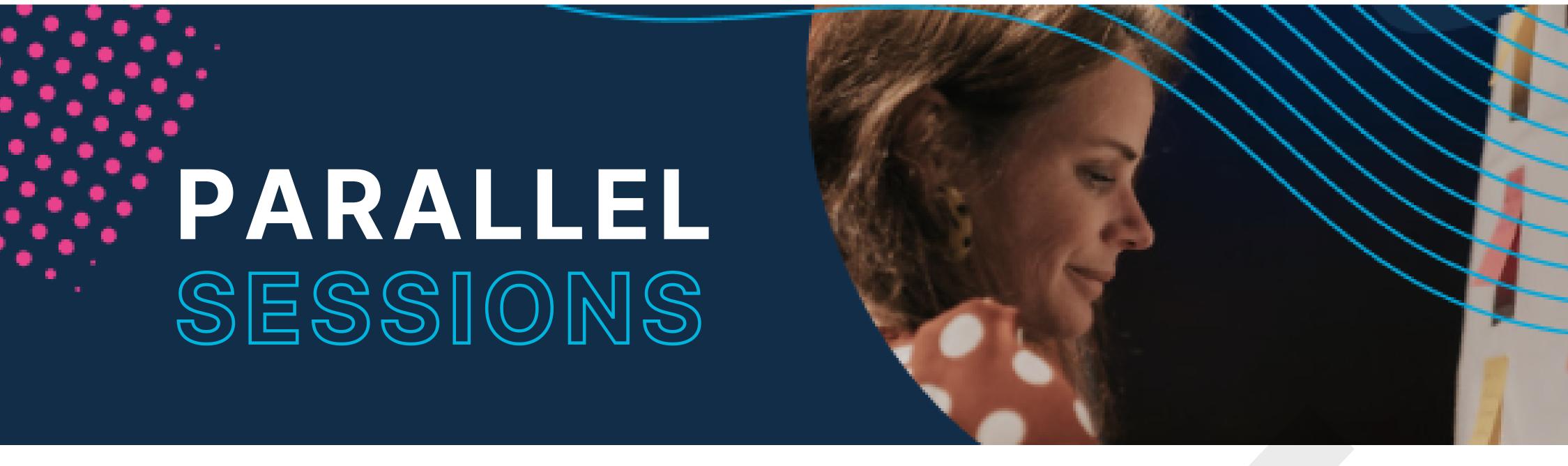
Workshop: "Volunteer engagement across the medicine's lifecycle and healthcare" (Part 2)

Moderators: Julien Delaye, François Hoüyez, EURORDIS

This session will explain how the new European Cooperation on Health Technology Assessment (HTA) functions upstream of national reimbursement decisions. It will include case studies presented by patient advocates and outline the role of EURORDIS internal taskforces for volunteers, including the HTA Taskforce and the Digital and Innovation Taskforce (DITA).

The session will also spotlight Community Advisory Boards (CABs), detailing how they operate, how they contribute at the clinical trial design stage, and the benefits of participating in such boards.

- Florian Innig, BKMF, Germany
- Gaetan Duport, European Haemophilia Consortium, France
- François Hoüyez, EURORDIS
- Rob Camp, EUPATI, Spain



Workshop: "Using Rare Barometer results for advocacy"

Moderators: Jessie Dubief, EURORDIS

This session will provide hands-on training for patient representatives on how to effectively use European, national, and disease-specific results from Rare Barometer surveys in their advocacy efforts. We will begin by explaining key concepts and statistics needed to use the survey results, and show you where to find this information in Rare Barometer publications (reports, factsheets, and dashboards).

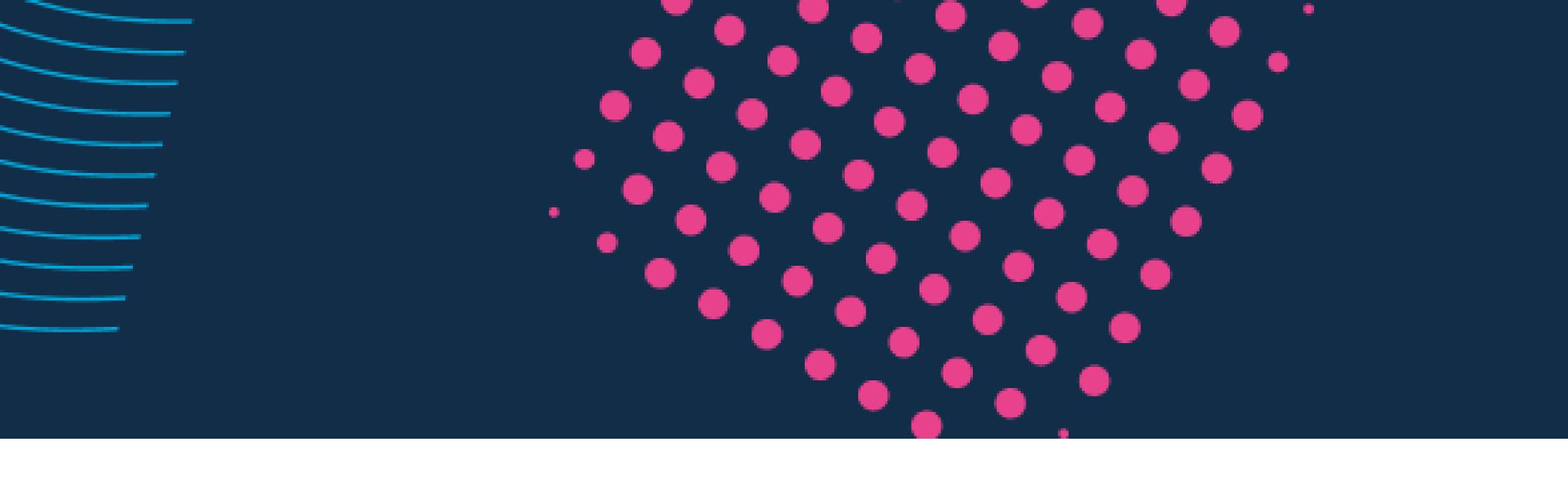
Patient representatives with prior experience using the survey results will then guide you through three writing exercises: creating a scientific poster, preparing an oral presentation for policymakers, and developing strategies and actions for a patient organisation.

These exercises will equip you with essential skills for evidence-based advocacy.

- Claudia Crocione, HHT Europe, Italy
- Dorica Dan, Romanian National Alliance for Rare Diseases
- Kirsten Johnson, Fragile X International, UK
- Nick Meade, Genetic Alliance UK
- Claas Röhl, NF Kinder, Austria

## With thanks to our Programme Committee:

Anja Helm, EURORDIS-Rare Diseases Europe
Anna Arellanesová, Rare Diseases Czech Republic
Graham Slater, EAT – Esophageal Atresia Global Support Groups
Jessie Dubief, EURORDIS-Rare Diseases Europe
Johan De Graaf, Nederlandse Hypofyse Stichting
Martina Bergna, EURORDIS-Rare Diseases Europe
Marta Augucēviča, Latvian Alliance for Rare Diseases
Raquel Castro, EURORDIS-Rare Diseases Europe
Sintija Bergmane, Latvian Alliance for Rare Diseases
Valentina Bottarelli, EURORDIS-Rare Diseases Europe
Virginie Bros-Facer, EURORDIS-Rare Diseases Europe



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