



EUROORDIS

MEMBERSHIP
MEETING

25-27
MAY

#EMM2023

STOCKHOLM, STOCKHOLMSMÄSSAN
EXHIBITION & CONGRESS CENTER



For more information,
please contact:
eurordis@eurordis.org



25 MAY THURSDAY



14.00
18.00

Room T5: Training on digital safety and literacy in the context of the ongoing healthcare digitalisation

Moderator: Jelena Malinina, EURORDIS

Contributors: Jan Penfrat, Senior Policy Advisor, EDRI; Guillaume Byk, Legislative Officer, European Commission

Objective:

- Gaining an understanding on the ongoing shift towards digitalised healthcare provision.
- Learning about simple ways how to avoid privacy, security and well-being risks using digital technologies.

A training will include: (1) a theoretical part co-organised with the European Commission representative and European Digital Rights (EDRI) - an association of civil and human rights organisations from across Europe; (2) a practical part, during which participants will be invited to test their acquired knowledge.

14.00
18.00

Room T2: Workshop on enhancing mental wellbeing in the rare disease community

Moderator: Matt Bolz-Johnson, EURORDIS.

Objective: To develop our understanding on how rare diseases impact mental wellbeing, in all aspects of daily lives, in schools, workplaces, communities and at home.

Through group discussion, informed by the experience of people living with a rare disease, we will identify which actions have worked well to support mental health within our communities and to ensure that everyone can thrive. The workshop will be an official event of European Mental Health Week, and engage member organisations representing diseases where mental health is reported as a co-morbidity and where their mental wellbeing needs remain unmet. Outcome: To launch the EURORDIS Mental Wellbeing Partnership Network

Read more about the workshop [here](#).

EMM 2023

26 MAY
FRIDAY



09.30

11.00

Room T1: EMM Plenary

Lifelong holistic approach and full inclusion in society

Moderator: Kirsten Johnson, EURORDIS & Fragile X Society, UK

- **Welcome speech** Maria Westerlund, Rare Diseases Sweden
- **Opening remarks** Avril Daly, President, EURORDIS & Retina International
- **Lifelong holistic approach and full inclusion in society** Maria Montefusco, Rare Diseases Sweden & EURORDIS
- **How Sweden and the Big 5 have inspired the holistic approach to the needs of people living with a rare disease and their families**, Anders Olauson, Agrenska, Sweden

Panel discussion: Parenting, being born, growing up, being an adult and ageing with a rare disease.

Panellists:

- Danielle Drachmann, Ketotic Hypoglycemia International, Denmark
- Jane Velkovski, Stop SMA, North Macedonia
- Adela Odrihocká, Rare Diseases Czech Republic
- Cees Smit, haemophilia advocate, Netherlands

11.00

11.30

Break

11.30

13.00

Moderated Networking Sessions

1. National actions which had an impact: What has worked in my country?

Room T5, Moderator: Lene Jensen, Rare Diseases Denmark

2. What makes a difference to achieve lifelong integrated care

Room T1, Moderator: Yann Le Cam, Chief Executive Officer, EURORDIS

3. How is my/my family member's Rare Disease impacting my mental health?

Room T6, Moderator: Matt Bolz-Johnson, EURORDIS

4. What barriers do we face while living with a rare disease and visible or invisible disability?

Room T2, Moderator: Raquel Castro, EURORDIS

13.00

14.30

Lunch

14.30

17.30

Workshops (4 parallel sessions)

These interactive workshops will explore the challenges and opportunities of living with a rare disease at each phase of life. Participants will be asked to take part in the discussions, by both asking questions as well as by sharing good practices and experiences.

*Please note that the same workshops take place twice, first on Friday and then on Saturday. Make sure you attend a different workshop on Friday and Saturday. **There will be a 30 min break in the middle of each workshop.***

1) Living with a rare disease in childhood, Room T6

Topics of discussion will include the Rare Barometer diagnosis survey results on children as well as successful programmes to support parents of children with a rare disease. Other topics related to childhood will be welcome.

Moderator: Anna Arellanesová, Rare Diseases Czech Republic

Note taker: Gulcin Gumus, EURORDIS

Panellists:

- Danielle Drachmann, Ketotic Hypoglycemia International, Denmark
- Jessie Dubief, EURORDIS
- Cecilia Stocks, Agrenska, Sweden
- Kristian Kristoffersen, FRAMBU, Norway

2) Living with a rare disease in adolescence, Room T1

Topics of discussion will include education, summer camps for adolescents, and transition from childhood to adulthood. Other discussion topics related to adolescence will be welcome.

Moderator: Raquel Castro, EURORDIS

Note taker: Rita Francisco, EURORDIS

Panellists:

- Jane Velkovski, adolescent living with SMA, North Macedonia
- Lars Nasset Romundstad, OIFE, Norway
- Mette Grenthoft, European Federation Williams Syndrome, Denmark
- Katja Ekholm, Karolinska hospital, Expert center for rare disease, Sweden
- Åsa Lundin, Linköping Expert center for rare disease, Sweden

14.30

17.30

3) Adult life with a rare disease, Room T5

Topics of discussion will include independent living – such as employment and housing – as well as wellness and mental health while living with a rare disease. Other discussion topics related adulthood will be welcome.

Moderator: Rebecca Tvedt Skarberg, EURORDIS & OIFE, Norway

Note taker: Julien Delaye, EURORDIS

Panellists:

- Adela Odrihocká, Rare Diseases Czech Republic
- Laura Rosillo Beneyto, International Federation for Spina Bifida and Hydrocephalus, Belgium
- Karin Högvall, Rare diseases Sweden
- Fanni-Laura Mäntylä, Finnish Institute for Health and Welfare, Finland

4) Ageing with a rare disease, Room T2

Topics of discussion will include a survey to map the needs of ageing bleeding disorder patients, as well as a working group of ERN ITHACA on ageing with intellectual disabilities. Other discussion topics related to ageing will be welcome.

Moderator: Geske Wehr, ACHSE & EURORDIS, Germany

Note takers: Julien Poulain, EURORDIS

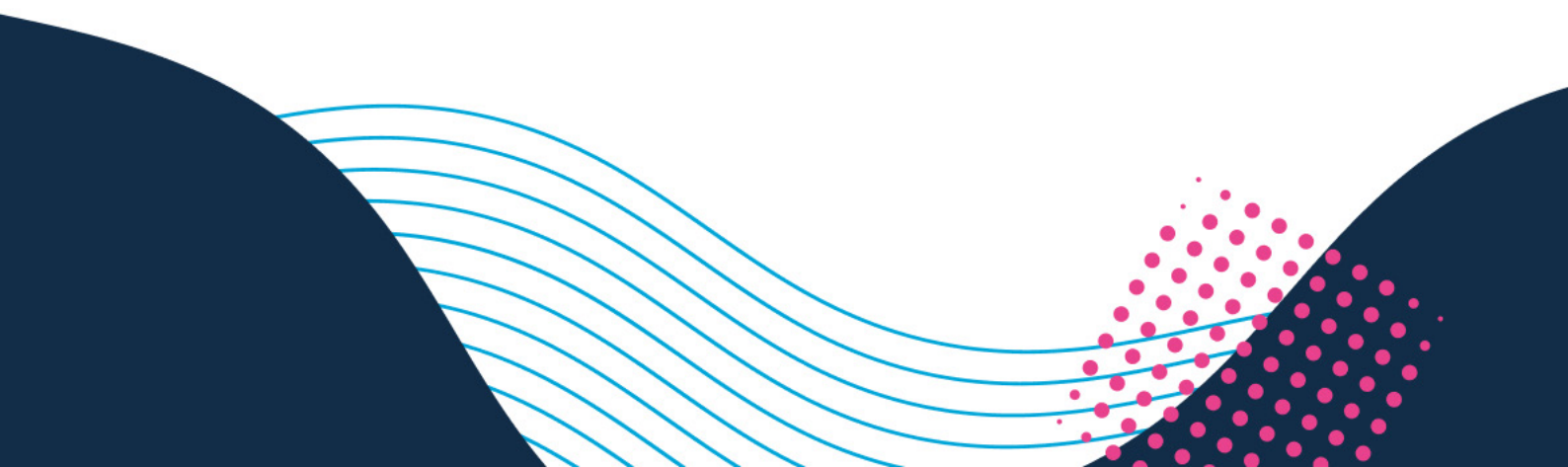
Panellists:

- Cees Smit, haemophilia advocate, Netherlands
- Kristine Jansone, European Haemophilia Consortium, Latvia
- Laura De Graaff, Erasmus MC, Netherlands
- Anne Hugon, ERN ITHACA, France
- Dorica Dan, Romanian National Alliance & EURORDIS, Romania

19.00

21.00

Welcome Dinner - Scandic Continental, Vasagatan 22, Stockholm



EMM 2023

27 MAY
SATURDAY



09.30

12.30

Workshops (4 parallel sessions) (repeating workshops of Friday afternoon)
There will be a 30 min break in the middle of each workshop.

- 1) Living with a rare disease in childhood, Room T6**
- 2) Living with a rare disease in adolescence, Room T1**
- 3) Adult life with a rare disease, Room T5**
- 4) Ageing with a rare disease, Room T2**

12.30

14.00

Lunch

PROGRAMME COMMITTEE:

- Sharon Ashton, EURORDIS
- Anna-Karin Björnström, Agrenska
- Valentina Bottarelli, EURORDIS
- Raquel Castro, EURORDIS
- Dorica Dan, Romanian National Alliance for Rare Diseases
- Malin Grände, Rare Diseases Sweden
- Kristina Gustafsson Bonnier, Rare Diseases Sweden
- Guðrún Helga Harðardóttir, Rare Diseases Iceland
- Anja Helm, EURORDIS
- Lene Jensen, Rare Diseases Denmark
- Stephanie Juran, Rare Diseases Sweden
- Yann Le Cam, EURORDIS
- Rebecca Skarberg, OIFE & EURORDIS

IN COLLABORATION WITH:

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