

HELSINKI

13/14 April 2026

General Annual Meeting



Funded by
the European Union



Tammisairaala, A-Tower
2nd floor, Paciuksenkatu 8, Helsinki, Finland

Monday 13 April 2026

ERN-EYE
Annual Meeting

AGENDA

08.30 REGISTRATION

OPENING SESSION (CHAIR: HÉLÈNE DOLLFUS)

09.00 - 09.05 Welcome address - **Hélène Dollfus**

09.05 - 09.20 Welcome address by local host - **Jukka Moilanen, Head of the Department of Ophthalmology & Tero Kivelä, Professor of Ophthalmology, University of Helsinki**

09.20 - 09.35 The past, present, and future of ERNs - **Helena Kääriäinen**

ERNS OUTLOOK (CHAIR: HÉLÈNE DOLLFUS)

09.35 - 10.05 Future of ERNs and 5Y HCPs evaluation - **Hana Horka**

10.05 - 10.15 HLM Rare - **Maurizio Scarpa**



10.15 COFFEE BREAK

ERN-EYE ACTIVITIES - PART I (CHAIR: JONI TURUNEN)

10.30 - 10.45 ERN-EYE overview of 2025 - **Hélène Dollfus**

10.45 - 11.05 Monitoring activities and ERNs - **Isabella Vacchi & Matthieu Stoll**

11.05 - 11.40 ePAG activities 2025 and outlook/priorities 2026 - **Dominique Sturz & Petia Stratieva**

11.40 - 12.10 ERN-EYE communication tools and trainings - **Caroline Wernert-Iberg**

12.15 GROUP PICTURE

12.30 LUNCH

13.30 - 15.00 GOVERNANCE BOARD

15.00 COFFEE BREAK

ERN-EYE ACTIVITIES - PART II (CHAIR: SUSANA NOVAL)

15.30 - 15.50 CPMS activities status - **Francesco Rotolo & Isabella Vacchi**

15.50 - 16.40 REDgistry and RETgistry - **Hélène Dollfus, Bart Leroy, David Keegan, Marieke Geldorf & Gillian O'Neill**

16.40 - 17.00 Guidelines and care pathways: Status - **Amélie Gavard**

17.00 - 17.20 Organisation of the national care pathways, referral systems to ERNs and incorporation of CPMS advice for rare and complex diseases - **Birute Tumiene**

17.20 - 17.30 A update on the Joint Action JARDIN - **Birute Tumiene**

17.30 - 18.30 National Integration Meeting (Chairs: Hélène Dollfus & Birute Tumiene)

17.30 - 19.45 SOCIAL PROGRAMME - VISIT OF THE EYE HOSPITAL

20.00 DINNER



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WORKING GROUP MEETINGS

08.00 - 09.00 **WG 3** (auditorium) / **WG 4** (meeting room) / **TWG 6** (teaching room)

09.00 - 10.00 **WG 1** (auditorium) / **WG 2** (meeting room) / **TWG 5** (teaching room)

10.00 **COFFEE BREAK**

ERN-EYE ACTIVITIES & ORPHANET (CHAIR: DAVID KEEGAN)

10.30 - 10.40 ORPHANET and HPO revision - **Amélie Gavard**

10.40 - 10.50 ORPHANET - an update - **Mickaël De Carvalho**

RARE DISEASE LANDSCAPE: UPDATES (CHAIR: BART LEROY)

10.50 - 11.05 ERDERA: accessible genetic testing for undiagnosed rare diseases - **Bart Dermaut**

11.05 - 11.25 Updates from ERDERA or ATMPs prioritization - **Daria Julkowska**

11.25 - 11.40 Inter-ERN transition working group - status of activities - **Susana Noval**

11.40 - 11.50 Realised - an update - **Johan Verbeeck**

11.50 - 11.55 EVICR.net - Clinical Research Network update - **Daniel Sanches Fernandes**

11.55 - 12.05 Open discussion



12.05 **LUNCH**

WRAP-UP SESSION – WORKING GROUPS (CHAIR: JONI TURUNEN)

13.05 - 14.05 Presentation by WG leaders

14.05 - 14.30 Open discussion

14.30 - 14.45 **CLOSURE SPEECH**

15.00 **END OF THE MEETING**

