



**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Eye Diseases (ERN-EYE)

Network Coordinator

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ERN-EYE General Annual Meeting Tallinn

26th to 27th March 2018,
Tallinn, Estonia

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ERN-EYE General Annual Meeting Tallinn

ERN-EYE Project Management Team

04/04/2018

Introduction

General Annual Meeting from March 26th – March 27th, 2018

After one year of existence, ERN-EYE organized its third important meeting from March 26th to 27th in Tallinn, Estonia. The General Annual Meeting gathered nearly 60 people from the HCPs of the 13 member countries of the network, as well as invited speakers.

The central part was dedicated to the second governance board

of the 2018 objectives that the board has approved; among them is the production of guidelines, the use of Clinical Patient Management System (CPMS) or the creation of an e-learning program.

In addition to the plenary sessions, nine ERN-EYE working groups were able to meet and

The General Annual Meeting made it possible to fix the goals for the year 2 of ERN-EYE and allowed to continue an active collaboration within the overall network and the working groups.

bringing together the representatives of ERN-EYE full members and patient representatives. During this board, a positive assessment of the first year of existence of ERN-EYE could be made: the main objectives of 2017 have been achieved or are in progress and new projects will be launched. These projects are part

define their roadmap for the coming months. Among their goals, registries and guidelines were identified as the most important ones. This meeting made it possible to fix the goals for the year 2 of ERN-EYE and allowed to continue an active collaboration within the overall network and the working groups.

ERNs in brief

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European Reference Networks (ERNs) are unique and innovative cross-border cooperation platforms between specialists for the diagnosis and treatment of rare or low prevalence complex diseases.

ERNs are virtual networks bringing together healthcare providers across Europe to tackle complex or rare medical conditions that require highly specialized treatment and a concentration of knowledge and resources. They are being set up under the EU Directive on Patients' Rights in Healthcare (2011/24/EU), which also makes it easier for patients to access information on healthcare and thus increase their treatment options.

The ERNs will be supported by European cross-border telemedicine tools, and can benefit from a range of EU funding mechanisms such as the "Health Program", the "Connecting Europe Facility" and the EU research program "Horizon 2020".



PLENARY OPENING SESSION

Welcome address – Inaugural welcome speeches

Hélène Dollfus, ERN-EYE coordinator & Artur Klett, ERN-EYE member, Tallinn, Estonia, host of the meeting



The General Annual Meeting was opened by Hélène Dollfus, coordinator of ERN-EYE and Artur Klett, the local host of the meeting, representative of the Eye Clinic of East Tallinn Central Hospital, member of ERN-EYE. Hélène

Dollfus presented the main topics of the meeting: guidelines, Clinical Patient Management System (CPMS), clinical trials and registries that are part of the goals for the second year of ERN-EYE.

ERN-EYE patient perspective

Christina Fasser, e-pag representative

The patient associations represented by Christina Fasser and Russel Wheeler opened the first part of the meeting with the patient perspective regarding ERN-EYE.

Christina Fasser pointed out that many people have come to the meeting and the fact that it is very gratifying to see the motivation of the participants.



The ERN-EYE project: Where are we now? Main achievements, challenges and plan for year 2

Hélène Dollfus, ERN-EYE coordinator



Hélène Dollfus cited the main achievements of the first year of ERN-EYE. Among those, the communication team was reinforced and the first workshop organized in October 2017 was a great success. She mentioned next the goals for ERN-EYE in the year

2: the upcoming call for new ERN-EYE members at the end of 2018 and the guidelines, the CPMS and the registries that are very important topics for ERN-EYE. The next meeting in Florence in October 2018 will allow presenting the progresses about those items.

CLINICAL PATIENT MANAGEMENT SYSTEM SESSION

CPMS general introduction and Commission expectations for ERNs

Caroline Paquier, ERN IT Project manager - External Consultant DG Sante Unit A4 – Information systems European Commission, Brussels, Belgium

The Clinical Patient Management System (CPMS) was launched by the European Commission (DG SANTE) on November 20th, 2017. It's a web-based application where healthcare professionals from the European Reference Networks can discuss real patient cases. This platform aims at supporting ERNs in improving the diagnosis and treatment of rare or

low prevalence complex diseases across national borders of Member States in Europe. Caroline Paquier from the EU Commission explained the state of achievement of the CPMS and the next steps. She mentioned for example the advantages of the system: secure exchange, a real time communication, medical image viewers, data transfer from



hospitals, crossover between ERNs, Database/reporting, KPIs and dedicated dataset.

CPMS state of the art and recent improvements, from the provider's side

Hany Mina, Openapp Project Manager for ERN CPMS, Dublin, Ireland



Hany Mina, Openapp project manager for ERN CPMS, demonstrated the available functionalities of CPMS system. He recalled the fact that the CPMS is not designed for

research purpose; it's a form of health care management system. He also explained to the audience all basic functionalities, how to work with panel and how to find patients in the system.

CPMS testing phase and ophthalmic customization

Dorothee Leroux, Project Manager of ERN-EYE

Dorothee Leroux presented the aims of the CMPS for ERN-EYE and the next steps. The

customization of the system is now finished; the next step is the launch of EyeClin.



CPMS general challenges (general discussion and preparation for working group sessions)

General discussion and preparation for working group sessions



During the general discussion that followed the CPMS plenary, the main point that was mentioned is the fact that ERN-EYE need to have a roadmap to know how to proceed with the legal issues of

each EU countries about data protection of patients to be able to begin to use the CPMS. This document will be provided by the Commission.

Flash presentations/ Call for collaboration

Agnese Suppiej (Italy), Petra Liskova (Czech Republic), H el ene Dollfus (France)

The clinical trials of three HCPs were presented to make calls for collaboration. Agnese Suppiej from Padova in Italy is working on Ataxia type 7 and prepares an 18-month clinical trial. Petra Liskova from Prague in Czech Republic is working on the Posterior polymorphous corneal dystrophy

with the aim of confirming OVOL2 and GRHL2 mutations in PPCD patients from other populations. Finally, H el ene Dollfus from Strasbourg in France works on cataract deafness on an affected family. All HCP members can join those projects if they are interested.



PLENARY REGISTRIES & ERNs

The rare diseases EU platform for registries

Simona MARTIN, European Commission, Joint Research Center (JRC)



During the meeting, a large place has also been given to the registries with the presence of Simona Martin, from the European Commission for the Joint Research Center. She mentioned that considerable progresses have been done during the last years. An EU platform for rare diseases registration has been created to

cope with the extreme fragmentation of data source across EU member states and to reach the critical number of patients for research and studies. The objective is the identification of the concrete interoperability needs to be provided by the EU platform.

Presentation of EU eye diseases registries during PLENARY: "ERN-EYE members existing registries"

Magda Meester-Smoor (Netherland), Sandra Valeina (Latvia), Luca Buzzonetti (Italy), Francesco Parmeggiani (Italy), Francesco Testa (Italy), Bart Leroy (Belgium)

Several HCP members presented the registry they currently use in their hospital. Netherland, Belgium, Latvia and Italy have registries for patients with ophthalmologic rare diseases that could be adjusted for ERN-EYE.

In the ensuing general discussion, participants agreed that legal issues and data storage are the most important questions to resolve before launching any registry.



Parallel: working groups session

WGs

In addition to the plenary sessions, nine ERN-EYE working groups were able to meet in two

parallel sessions and define their roadmap for the coming months. Among their goals, registries and

guidelines were identified as the most important ones.

ERN-EYE WGS leaders

| WG number | Theme | Chairs |
|-----------|---------------------------------------|--|
| WG1 | Retinal Rare Eye Diseases | B.Leroy (UG) and M. Larsen (Rigshospitalet) |
| WG2 | Neuro-ophthalmology Rare Diseases | A.Petzold and S. Wong (MEH) |
| WG3 | Pediatric Ophthalmology Rare Diseases | B. Lorentz (UKGM) and J.Ashworth(MREH-MAHSC) |
| WG4 | Anterior Segment Rare Eye Diseases | T. Reinhard (UMCF) and P. Liskova (HPH) |

SECOND GOVERNANCE BOARD

ERN-EYE members and ERN-EYE advisory board

The central part of the Tallinn Meeting was dedicated to the second governance board bringing together the representatives of ERN-EYE full members and patient representatives. During this board, a positive assessment of the first year of existence of ERN-EYE could be made: the main

objectives of 2017 have been achieved or are in progress and new projects will be launched. These projects are part of the 2018 objectives that the board has approved; among them is the production of guidelines, the use of Clinical Patient Management System (CPMS) or the creation of an e-learning program.



PLENARY GUIDELINES & ERNs

Pr H el ene Dollfus mentioned in introduction to this plenary session an ERN-EYE survey about guidelines (title, rare disease concerned, legal recognition, publication dates or revision dates, author(s) details). The results of the survey show that there are 11 different guidelines from 6 countries mainly related to the WG1 of ERN-EYE.

Recommendations' on ERNs & Clinical Practice Guidelines - conclusions of RD-ACTION workshop

Victoria HEDLEY, RD-Action Policy Manager, Newcastle University John Walton Muscular Dystrophy Research Centre, Newcastle, UK



Victoria Hedley, RD-Action Policy Manager, presented the results of a RD action workshop on guidelines organized on 6th and 7th December 2017 at Istituto Superiore di Sanita in Rome, Italy, with all ERNs. This workshop allowed answering many

questions about this crucial matter for all the Rare Disease Community. This presentation was followed by a very interactive discussion regarding guidelines challenges for RED, especially at an international level.

Parallel: Transversal working groups session

In addition to the plenary sessions, six ERN-EYE transversal working groups were able to meet in two parallel

sessions and define their roadmap for the coming months.



| TWG number | Theme | Chairs |
|------------|---|--|
| TWG5 | Low Vision and Daily Life Patient Group | S. Mohand-Said (CHNO-XV-XX) and D. Keegan (MMUH) |
| TWG6 | Genetic Diagnostics | G. Black (MREH- MAHSC) and F. Cremers (RUMC) |
| TWG7 | Registries and Epidemiology | C. Boon (LUMC/AMC) and K.Khan (JUH) |
| TWG8 | Research | D. Fisher (EKUT) and C.Boon (LUMC/AMC) |
| TWG9 | Education, Training & Guidelines | T. Wheeler-Schilling (EKUT) and H. Dollfus (HUS) |
| & TWG10 | Quality, Communication & Management | H. Dollfus and D. Leroux (HUS) |

Plenary: Wrap-up session & general conclusions

WG and TWG leaders

The meeting closed with a discussion about the next steps for ERN-EYE, a roadmap for the next months (inventory missions,

guidelines, genetic testing, Guidelines and teaching, registries), the dates of the next meetings and an agenda for 2018-2019.



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