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**European
Reference
Network**

for rare or low prevalence
complex diseases

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

ERN-EYE GENERAL ANNUAL MEETING

21st to 22nd March 2019,
Prague, Czech Republic

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ERN-EYE GENERAL ANNUAL MEETING

ERN-EYE Project Management Team

28/03/2019

Introduction

3rd General Annual Meeting – March 21st- 22nd, 2019

ERN-EYE organized its 3rd General Annual Meeting from March 21st to 22nd in Prague, Czech Republic. It gathered nearly 70 people from the HCPs of the 13 member countries of the network, as well as invited speakers. The central part of the meeting was dedicated to the third governance board bringing together the representatives of ERN-EYE full members and patient representatives. During this board, a positive assessment of the actions of ERN-EYE in 2018 could have been made: the main objectives have been achieved or are in progress and new projects will be launched very soon.

The second part of the meeting was devoted in particular to the research with H el ene Le Borgne who gave the views of the EU and some ERN-EYE members who presented their work into the ERN-EYE transversal working group "Research".

As a red line, a great part of the meeting was dedicated to the CPMS with the presence of Dr Laura Muring, ERN-EYE MD fellow 2018-19, ophthalmologist, and Francesco Rotolo, IT specialist, who constitute the new ERN-EYE CPMS Helpdesk.

Finally, a large place has been given to the registries with Pr H el ene Dollfus who mentioned the strategy and the planning for the coming year and to the e-learning with Dorothe e Leroux, ERN-EYE Project Manager, who talked about the strategy, the program and the timeline.

This meeting made it possible to fix the goals for the year 3 of ERN-EYE and allowed to present all the ongoing actions of the network.

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".

A positive assessment of the actions of ERN-EYE in 2018 could be made: the main objectives have been achieved or are in progress and new projects will be launched very soon.

WELCOME SPEECHES & OBJECTIVES OF THE MEETING

Welcome address – Inaugural welcome speeches

Hélène Dollfus, ERN-EYE coordinator & Petra Lišková, ERN-EYE member, Prague, Czech Republic, host of the meeting; Pr Tomáš Zima, Rector of the Charles University.



The workshop was opened by Hélène Dollfus, coordinator of ERN-EYE, Petra Lišková, local host,

representative of the General University Hospital in Prague, member of ERN-EYE, Pr Tomáš Zima, Rector of the Charles University. Petra Lišková highlighted the fact that the General Hospital in Prague is the only HCP involved in the ERN-EYE from the

Czech Republic, the largest ophthalmology reference centre in the Czech Republic and 3rd oldest ophthalmology department in Europe.

2018 report on ERN-EYE activities, achievements and future challenges

Hélène Dollfus, ERN-EYE coordinator

Hélène Dollfus cited the main achievements of the second year of ERN-EYE. Among those, a helpdesk was created to help members with the CPMS. She mentioned next the goals for ERN-EYE in the year 3: the upcoming

call for new ERN-EYE members at the end of 2019, the guidelines, the CPMS and the registries are very important topics for ERN-EYE. In this objective, the next meeting in November 2019 will be dedicated to research.



PLENARY SESSION: BEING AN ERN-EYE MEMBER, WHAT DOES IT MEAN? (CHAIR: HÉLÈNE DOLLFUS)

Being an ERN-EYE member, what does it mean?

Hélène Dollfus, ERN-EYE coordinator



Hélène Dollfus reminded to all participants what is an ERN, what it means to be a member, which are the working groups and who are the working group leaders. She also named the missions of the HCPs and the major points for ERN-EYE:

CPMS, Guidelines , E-Learning and Collaborative publications.

All these points are important for ERN-EYE to continue to exist.

Feedback on an audit: What is expected from an ERN-EYE HCP

Artur Klett, ERN-EYE member, Tallinn, Estonia

The East Tallinn Hospital in Estonia had last year an on-site audit. Artur Klett explained what it was expected from him. He explained that the audit happened in September 2018 on site. The first results were delivered in October and the final results in

December. Since the audit, a specific rare eye disease registry and a specific protocol for the MDT meeting for REDs were created. Artur Klett reminded also that all documents have to be prepared in advance.



Benefits and added value: Feedback from hosts of short exchanges programs

Markus Preising, ERN-EYE member, Giessen, Germany



Markus Preising talked about his experience as host of a short exchange. Gita Taurina from Riga, Latvia, went to Giessen thanks to the ERN-EYE short

exchange program. She could be able to see the laboratory, the patient database, the patient testing and all the work flow. It was a successful exchange.

Isabelle Audo, ERN-EYE member, Paris, France

The team of Isabelle Audo welcomed Christina Eckmann-Hansen, optometry study, PhD student from Denmark. She could visit the sequencing genetic clinics, the clinical research center, and see the adaptive optics platform.

It was short but intense; there were interesting interaction and exchange on mutual practice. A discussion happened on several items including career, future of clinical trials, high-tech and exam such as adaptive optics.



What is expected from ERNs and ERN members? Monitoring of ERNs

Hélène Le Borgne, DG Santé, European Commission (webconference)



In name of the European Commission, Hélène Le Borgne explained the history of the ERNs and what is expected from them. Among the missions of the ERNs, there are a general organisation

and coordination, patient care, multidisciplinary approach, research, education, guidelines and communication and dissemination.

Patient's opinion

Christina Fasser, ePag representative

Christina Fasser, ePag representative, expressed her admiration on what has been achieved in 2 years. She is aware that at the beginning the network had to put a structure and is glad that the CPMS now works. For her, the cooperation in working

groups can be really good. The aim is now to do that patients know ERNs in Europe and define the patient pathway in each country. This expertise should reach the patients and the ophthalmic community.



PLENARY SESSION: THE MAJOR OBJECTIVES FOR ERN-EYE

CPMS/EYECLIN SESSION (CHAIR: HÉLÈNE DOLLFUS)

Presentation of the CPMS: generic and dedicated datasets

Dorothee Leroux, ERN-EYE project manager, Strasbourg, France



Dorothee Leroux presented the Clinical Patient Management System (CPMS): she evoked the different phases of construction (customization and validation by the

WG leaders) and what are the main objectives (bring the best expertise to all patient in Europe, discuss difficult cases).

How to use the system with the helpdesk team

Francesco Rotolo, ERN-EYE IT specialist, Strasbourg, France



Francesco Rotolo takes part to the new CPMS helpdesk with Laura Mauring. He explained the technical aspects of the CPMS: how to connect, how to create a panel, what are the different panel roles,

how to invite members and schedule a meeting, what is the common and the specific dataset. ERN-EYE members could ask him questions during the whole meeting.

In practice => Clinical cases examples

Laura Mauring, ERN-EYE CPMS Medical fellow, Strasbourg, France

Laura Mauring is the ERN-EYE medical fellow for one year and is part of the helpdesk to provide medical help to the ERN-EYE

members on the CPMS. She presented medical cases as an example and how to discuss them on the CPMS.



BASIC REGISTRY SESSION (CHAIR: HÉLÈNE DOLLFUS)

General introduction: The registry challenge : why and when ?

Hélène Dollfus, ERN-EYE coordinator



Hélène Dollfus presented the registry challenge for ERN-EYE. Our network members are currently involved in 14 identified registries : 1 is related to Working Group 1 (Retinal RED) only, 2 to WG2 (Neuro-Ophthalmological RED), 1 to WG4 (Anterior Segment RED), others (10 registries) concerned all inherited

eye disorders. Data is stored in following countries: United Kingdom (3), Germany (1), Belgium (1), Italy (3), Latvia (3), Netherlands (1), two not known. The priority is now to have a basic registry with a minimal dataset (genetic data, epidemiology). This project will be submitted in the next European Call.



Dublin meeting report: the ERN-EYE basic registry project

Russell Wheeler, ePag representative & Dorothee Leroux, ERN-EYE project manager

Russell Wheeler and Dorothee Leroux made a feedback on the meeting held in Dublin in January about the basic registry project. A map of the EU resources available for RED registries is

available and the classification and ontology for rare eye disease was reviewed last year as a preliminary work. They presented also the next objectives and the ERN-EYE specific needs.



PLENARY SESSION “FLASH INFORMATION”

GUIDELINES SESSION: WHERE ARE WE? WHERE WE GO?

(CHAIR: HÉLÈNE DOLLFUS)

General discussion: ERN-EYE strategy regarding guidelines– Planning – (Guidelines examples)

Hélène Dollfus, ERN-EYE coordinator



Hélène Dollfus presented the guidelines objectives for ERN-EYE. As an expert centre network, ERN-EYE is mandated to produce guidelines, to spread the good practices across Europe. ERNs are evaluated on guidelines production. Health

care guidelines provide recommendations that describe in detail what the recommended action is and under what circumstances it should be performed. The ERN-EYE strategy was actively discussed.

E-Learning Strategy for ERN-EYE: existing tools, program and timeline

Dorothee Leroux, ERN-EYE project manager & Hélène Dollfus, ERN-EYE coordinator

Knowledge sharing, education and training are full part of the ERN-EYE spirit and strategy. That's why ERN-EYE will launch an e-learning program. This complete course will contain 4 modules and require a Learning Management System – LMS (mandatory to achieve the

goals). Each module contains a number of hours equivalent to a training week (between 28 and 31 hours). The first module is made up by 30.5 h. The 1st module will be launched in the following months.



GUIDED WG PARALLEL SESSIONS (WORK ON THE 3 MAJOR THEMES)

Working Groups 1, 3 & 4

The Working Groups 1, 3 and 4 had parallel sessions to discuss about the CPMS, e-learning and guidelines. They talked about how to manage the cases in the CPMS and they scheduled monthly meetings. They also discussed the next objectives of each working

group. On the next day, they also had a special CPMS session with the helpdesk team to deal with practical and technical questions.



THIRD GOVERNANCE BOARD

ERN-EYE members and ERN-EYE advisory board



The central part of the meeting was dedicated to the third governance board bringing together the representatives of ERN-EYE full members and patient representatives. During this board, a positive assessment

of the actions of ERN-EYE in 2018 could have been made: the main objectives have been achieved or are in progress and new projects that will be launched very soon.

PLENARY SESSION: RESEARCH SESSION (Chair: H  l  ne Dollfus)

EU Commission's views on research for ERNs

H  l  ne Le Borgne, DG Sant  , European Commission (webconference)



H  l  ne Le Borgne spoke about research in the ERNs. All ERNs agreed on a common definition of ERN research. There is a general consensus to work closely with the different work packages of the European Joint Program for Rare Diseases (EJP-RD).

Five actions points have been identified and discussed :

1. Conceptual document: draft on ERN research
2. Information portal (2019)
3. Meeting with research infrastructures (November 2019)
4. ERN RWG EMA Contract
5. Work across ERN on registries

Main Outlines of EJP – Where are we as an ERN?

Hélène Dollfus, ERN-EYE coordinator

Hélène Dollfus explained the European Joint Program for Rare Diseases . It regroups all research grants dedicated to Rare Diseases . There are 4 pillars: funding, coordinated access, helpdesk & innovation and training & capacity building. An ERN cannot apply to a

research project itself (except CEF-call), a member has to apply. If there is a H2020 call, the ERN cannot be the applicant but the different HCPs can.



ERN-EYE study in outcome of cataract surgery in retinitis pigmentosa: challenges for research

Thanh Nguyen, ERN-EYE TWG8 member, Leiden & Amsterdam, The Netherlands



Thanh Nguyen presented a study in outcome of cataract surgery in retinitis pigmentosa. The aim is to evaluate the subjective and objective visual benefit after cataract surgery in patients with retinitis pigmentosa and to

evaluate the perioperative and postoperative complications after cataract surgery in patients with retinitis pigmentosa. Research protocol is available on extranet of ERN-EYE.

Challenges and Future issues for the genetic testing group in the ERN-EYE (Chair: Hélène Dollfus)

PLENARY SESSION: REPORT OF WG LEADERS

Michael Larsen, Chair of WG1, Markus Preising, Chair of WG3 & Daniel Böhringer, Chair of WG4

Michael Larsen, Markus Preising and Daniel Böhringer gave feedbacks about what they talked about in their working groups. In brief, main points were the CPMS, guidelines and the e-learning. WG1 could schedule meetings to discuss

the CPMS cases, WG4 announced some new publications and WG3 accepted to collaborate with WG4 on a guideline on aniridia.



Plenary session: patients outcomes for research

Including patients in core outcome set development- A focus on the Delphi survey

Alice Biggane, MiRoR Project Research Fellow, Liverpool, UK



Alice Biggane explained what is a Delphi survey and what is its utility. It was developed in the 1950s. The method is a group of experts who anonymously reply to questionnaires and subsequently receive feedback in the form of a

statistical representation, after which the process repeats itself. The goal is to reduce the range of responses and arrive at something closer to expert consensus i.e. what is truly important.

PLENARY SESSION: Patient Involvement in Identifying Unmet Needs on Clinical Practice Guidelines – Example Of ERN Reconnect

Charissa Frank, ERN-ReCONNECT ePAG representative, Belgium

Charissa Frank came to the ERN-EYE meeting to give the point of view of an ePag of another ERN. She explained that through the active participation in ReCONNECT and disease working groups, the ePAGs were able to fully represent

their RD patient community and bring in the patients' perspective. Action and pro-action are the roots for change. The ePAGs input helped build/improve the relationships with clinicians bringing mutual respect and appreciation.

