



European Innovation  
Partnership on Active  
and Healthy Ageing

PARTNER

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# Annual Report

[2019] – 1st January to 31st December 2019

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This document was produced for review by the European Alliance for Vision Research and Ophthalmology (EU EYE), Belgium.

# THE ORGANISATION

The EU EYE constituency comprises of ophthalmological societies representing over 9,000 medical specialists active in clinical medicine, research, education and training in 100 countries.

The EU EYE works towards building a respected forum which brings medicine, science, education and advocacy together and is accessible to all – citizens, decision makers, research and healthcare workforce.

## EU-EYE Members

- European Society of Cataract and Refractive Surgeons **ESCRS**
- European Society of Retina Specialists **EURETINA**
- European Glaucoma Society **EGS**
- European Association for Vision and Eye Research **EVER**
- European Eye Bank Association **EEBA**
- European Society of Cornea and Ocular Surface Disease Specialists **EuCornea**
- European Association for the Study of Diabetes/Ophthalmology Section **EASDec**
- European Paediatric Ophthalmological Society **EPOS**
- European Vision Institute **EVI**

## EU-EYE Board

Carlo Traverso	President/EGS Representative
Paul Rosen	Vice-President / ESCRS Representative
Jesper Hjortdal	Secretary / EEBA Representative
Tunde Peto	Treasurer / EASDec Representative
Giuseppe Querques	EURETINA Representative
Massimo Nicolò	EURETINA co-opt Representative
Marcela Votruba	Board Member / EVER Representative
Marie-José Tassignon	Board Member / ESCRS Representative
José Güell	Board Member / EuCornea Representative
Darius Hildebrand	Board Member/EPOS Representative
Hendrik Scholl	Board Member/EVI Representative

## EU-EYE Objectives

We advocate for people-centred eye health care with an on-going commitment to the integration of research priorities, policies and strategies in eye health at European level.

Our varied portfolio of activities aim to open up the space for the patient empowerment process and the creation of new translational and fundamental research networks in our discipline.

## ACRONYMS AND ABBREVIATIONS

<b>EIP AHA</b>	European Innovation Partnership on Active Healthy Ageing
<b>EMA</b>	European Medicines Agency
<b>EOSC</b>	European Open Science Cloud
<b>HCPWP</b>	Healthcare Professionals Working Party
<b>HPP</b>	Health Policy Platform
<b>EXPH</b>	Expert Panel on Investment in Health
<b>STAMP</b>	Expert Group on Safe and Timely Access to Medicines for Patients
<b>WHO</b>	World Health Organisation
<b>EVICR.net</b>	European Vision and Clinical Research Network

## Summary

In 2019 the EU-EYE continued to strengthen its organisational capacity for advocacy work and a number of societies have appointed new representatives with the prospective addition of EVICR.net, as a new member from January 2020.

In February the EU EYE has been accepted as an eligible organisation of the European Medicines Agency. The organisation has received numerous request by the Agency and its related organisations to compile a list of patient societies for EMA's work and to identify clinical experts for specific projects. The EU EYE has also applied for membership to the Healthcare Professionals Working Party (HCPWP) of EMA for the mandate 2019–2021.

The organisation reached its target of 10 activities for its commitment to the EIP AHA partnership network and reinforced the message for integrated eye care within the B3 Action Group.

Preparations continued for the endorsement of the European Open Science Cloud (EOSC) Declaration with intention to formally enter the EOSC process and formulate activities within the EU-EYE member societies on the sharing of research data in ophthalmology.

The participation in the public consultations continued (Good practice guidance / communication on medicines' availability; Safety of medicines campaign – info-cards; Role of Big data in medicines evaluation; Review Disability Strategy; MULTI-ACT consultation on patient engagement).

Monitoring of activity was introduced for the new website.

The EU EYE continues to improve its visibility and gaining entries in vision related projects such as the EU-funded Galahad project: <https://galahad-project.eu/links/>

## EU EYE Activities 2019

### 1. General Organisation

In late 2019 the EU EYE has thanked Professor Einar Stefánsson for his dedication and commitment to the advocacy efforts of the ophthalmology community as his term of office came to its end. Professor Stefánsson was one of the founder members of the EU EYE in 2015 and he has led the EU EYE in the advocacy arena during its formative years.

Professor Stefánsson was succeeded in the EURETINA representation by Giuseppe Querques with Massimo Nicolò as a co-opt representative.

Marcela Votruba has replaced Leopold Schmetterer in the representation of EVER. Hendrik Scholl has replaced Thomas Wheeler-Schilling in the representation of EVI. Darius Hildebrand is the current EPOS Representative.

The EU EYE Code was finalised and it is publicly accessible at:

[http://www.eueye.org/wp-content/uploads/2019/01/CodeConduct\\_EUEYE\\_2019.pdf](http://www.eueye.org/wp-content/uploads/2019/01/CodeConduct_EUEYE_2019.pdf)

This Financial and Disclosure Policy Document provides guidelines on: sponsoring, grants, donations and loans; and sets provisions to manage contact with industry and conflicts of interest for individuals selected as EU EYE representatives.

The production of the tailored monthly e-newsletter on policy developments was resumed aiming to improve member awareness of policy developments in the areas of health, research, training and education across Europe.

The mapping of internal knowledge and expertise continues, identifying expertise and recruiting members for forthcoming activities.

The monitoring of activity at the EU EYE website was completed in July 2019. The first year report indicates 90% of new users since the launch of the new website in May with over 50% of visitors coming from the USA.

The EU EYE has considered a strategy to improve its visibility among the ophthalmology community and it has gained entries in vision related projects such as the EU-funded Galahad project: <https://galahad-project.eu/links/>

## 2 ADVOCACY

### European Medicines Agency

The EU EYE has successfully passed the eligibility confirmation process of the European Medicines Agency and it is now listed as one in EMA's website:

<https://www.ema.europa.eu/en/partners-networks/healthcare-professionals/eligible-healthcare-professionals-organisations>

Inclusion in EMA's eligibility list qualifies the organisation to apply for membership to EMA's Healthcare Professionals Working Party (HCPWP)<sup>1</sup> of EMA and receive requests for representation to a number of policy making events.

The portfolio of activities continued to expand as a result with representation by:

- Massimo Nicolò in the 5th stakeholder conference on biosimilar medicines Brussels. 30.10.2019;
- Mor Dickman in the EMA Regulatory Science to 2025 Human Stakeholders' Workshop, Amsterdam; 18-19.11.2019;
- Ioanna Psalti in the Annual HCPWP, EMA, Amsterdam; 20.11.2019

Support was also provided to the EUnetHTA in successfully locating clinical experts for a number of Joint Assessments exercises.

Diego Ponzin, EEBA continues to support the EU EYE in developing appropriate actions regarding regulatory issues emerging in the development of ATMPs.

### European Commission

The EU EYE has received invitation to participate in the 11th STAMP meeting, DG Pharmaceuticals-B5, Brussels; 15 March 2019.

EU EYE members were encouraged to apply to a number of calls issued by the European Commission for clinical experts on medical devices and in vitro diagnostic medical devices. Announcement of results are expected in 2020.

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<sup>1</sup> Healthcare Professionals Working Party which provides recommendations to the EMA and its scientific committees on all matters of interest in relation to medicines. The HCPWP has 28 members with 20 being drawn out of EMA's eligible organisations list.

## EIP AHA & HPP

The organisation has reached its target of activities for its EIP AHA Commitment entitled [Creating a forum to maximise the integration of research priorities, policies and strategies in eye health](#) and accessible in the online portal of the European Commission.

The EU EYE is currently in the process of updating its commitment and of aligning its activities to the priorities of the EIP AHA for 2020–2021.

The EU EYE remains a registered user of the Health Policy Platform.

## Public consultations, hearings and events

Engagement continues with the consultation and decision making process of the European Commission through participation in the following consultations:

- Good practice guidance /communication on medicines' availability in April;
- Safety of medicines campaign – info-cards in April;
- The role of Big Data in medicines evaluation in April;
- The Review of the Disability Strategy in October;
- The MULTI-ACT consultation on patient engagement in December

Other consultations requiring input by individuals were considered by Board members:

- Use of patient registries for regulatory purposes (EMA);
- X-linked R. pigmentosa (Paediatric Committee, EMA);
- Clinical trials transformation initiative (EMA);
- Preparedness paediatric clinical trials (EMA);
- WHO document on data integrity for medicinal products.

## Other

The EU EYE has approached the European Patient Forum regarding the formation of patient societies for families with chronic diseases with specific interest on metrics on Quality of Life for evaluating parental well-being.

The EU EYE maintains a publicly accessible list of ophthalmic patient societies. The list is continuously updated.

Preparations continued for the endorsement of the European Open Science Cloud (EOSC) Declaration and the formulation of activities on sharing data in ophthalmology research with intention to formally enter the EOSC process.