



European Innovation  
Partnership on Active  
and Healthy Ageing

PARTNER

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# Annual Report

[2020] – 1st January to 31st December 2020

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# 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 Full 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 [EPOS](#)
- European Vision Institute [EVI](#)
- European Vision Clinical Research network [EVICR.net](#)

## EU-EYE Associate Members

- COST Action CA18116 Aniridia network [Aniridia-Net.eu](#)

## 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 & EVICR.net Representative

## General Assembly Representatives

Current Board Members represent their individual organisations at the General Assembly. Associate member Aniridia-Net is represented by Neil Lagali.

## 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>EXPH</b>	Expert Panel on Investment in Health
<b>HCPWP</b>	Healthcare Professionals Working Party
<b>HPP</b>	Health Policy Platform
<b>PCWP</b>	Patients and Consumers Working Party
<b>STAMP</b>	Expert Group on Safe and Timely Access to Medicines for Patients
<b>WHO</b>	World Health Organisation
<b>YIO</b>	Yearbook of International Organisations

## Summary

In 2020 the EU-EYE welcomed the addition of EVICR.net, as a new member in January followed by the COST Action CA18116 Aniridia network in March.

The organisation started reviewing its role within the next generation of European Partnerships under Horizon Europe. Further engagement with EU institutions and agencies continued primarily with identifying clinical experts and with an intensified participation in public consultations and COVID-19 related efforts [Guidance (v3) for sponsors on how to manage clinical trial during Covid-19 pandemic (including a series of subtopics); European Strategy for data; White paper on AI: “Towards an ecosystem for excellence and trust”; Pharmaceutical Strategy – Timely patient access to affordable medicines: Part I – Roadmap; Guideline on registry-based studies; UNESCO Recommendation on Open Science].

A series of proactive communications were undertaken on topics such as use of hydroxychloroquine and Chloroquine for COVID-19; safety and quality concerns on variations in ATMP preparations across Europe; inclusion of ocular system in the AESIs of COVID vaccines; impact of COVID-19 in care services and clinical trials in eye diseases particularly safety of participants and research quality.

International visibility and awareness was improved among the greater ophthalmology community with an entry in the Yearbook of International Organisations and through the virtual booths held at the ESCRS and the EURETINA events in October. The website traffic doubled in overall visitor numbers compared to 2019.

## EU EYE Activities 2020

### 1. General Organisation

In January 2020 the EU EYE welcomed in its membership the [EVICR.net](#) with Hendrik Scholl as its representative and in March the Aniridia-net as its first Associate Member represented by Neil Lagali.

The organisation has renewed its eligibility status with the European Medicines Agency (EMA) in December and remains [registered in the EU Transparency Register](#) and [listed in the EMA's website](#).

The organisation remained a committed partner of the European Innovation Partnership on Active Healthy Ageing ([EIP AHA](#)) and a registered user of the Health Policy Platform ([HPP](#)) of the European Commission.

The EU EYE communications with the greater ophthalmology community were reorganised during 2020 as a result of the COVID-19 outbreak. The monthly newsletter on policy developments was replaced with timely alerts and a series of briefings focusing on emerging concerns of patients, healthcare professionals in ophthalmic practices and researchers such as access to care, shortages of medicines, changes in the management of clinical trials etc.

The EU EYE has awarded its recognition marks to its member organisations as an acknowledgement of the contribution and the continuous support of the different organisations to the alliance. Use of the mark is purely voluntary and in whichever way each member organisation chooses to e.g. in web materials, presentations etc.



The EU EYE has gained entry in [the Yearbook of International Organisations](#) (YIO)\* and it remains listed in the [Horizon2020 Galahad](#) site for the duration of the project\*\*.

In October 2020 and during the 38th Congress of the ESRCs and the EURETINA 2020 Virtual, the EU EYE held interactive virtual booths at each event and launched a short film on the organisation's evolution and work since its inception in 2015.

\* YIO is a comprehensive database of intergovernmental (IGOs) and international non-governmental organizations (INGOs) worldwide; published in English and Chinese.

\*\*Galahad is an initiative of the Photonics Public Private Partnership supported by Photonics 21; its primary objective is to improve screening and basic diagnostics for glaucoma.

The renewed website has showed a marked increase in traffic with 100% increase in total No. of website visitors and No. of sessions. The following countries have shown the most prominent % increase from the 2019 figures:

Spain (308%);      China (240%);      France 158%;      USA (92%)

## 2    ADVOCACY

### European Medicines Agency

The EU EYE continued to support the EMA and associated organisations such as the [EUnetHTA](#) in locating clinical experts for:

- dry eye diseases;
- 9<sup>th</sup> Joint Assessment on brolocizumab;
- 13<sup>th</sup> Joint Assessment on Satralizumab.

During the outbreak of the COVID-19 disease, the EU EYE engagement with the EMA was intensified in general through participation in online meetings and consultations (details under [Public consultations, hearings and events](#)) and more specific by disseminating relevant information (e.g. access to portals on COVID-19 Data, vaccination information, etc). The EU EYE's own mapping of internal knowledge and expertise was diversified to include expertise in epidemiology and clinical care of COVID-19 patients from within the hospital settings of the Board Members. Further input was provided to the EMA Dissemination strategy regarding COVID-19 vaccines safety in November and to the EMA's 'new brand narrative' and the proposed mission statements in December.

The following topics were proactively brought to the attention of the agency:

- Safety and quality concerns on variations in ATMP preparations across Europe;
- Input to EMA's evaluation for authorisation of Dexamethasone Taw for treating hospitalised adult patients with COVID-19.
- Compilation and submission of list of ophthalmic medicines which were or expected to be in shortage as a result of Covid;
- Concerns about treatment cessation in eye diseases including clinical trials of ATMPs & injectable treatments;
- Concerns on safety of participants and quality of research in clinical trials during COVID-19;
- Concerns about the lack of inclusion of the ocular system in the list of AESIs in the monitoring of COVID vaccines.

The organisation was invited to participate in the EMA Collaborating Expert Programme and will be identifying potential candidates in 2021.

## European Commission

Dominique Bremond-Gignac has been appointed by the European Commission as advisor to the Screening panel in the field of medical devices.

We continue to support our members with tailored advice in their applications to expert panels or committees of the EU institutions and agencies.

## EIP AHA & HPP

The EU EYE welcomed the highlighting of patient needs with chronic eye diseases featuring in the [Blueprint personas](#), a policy tool developed by the EIP on AHA stakeholders in collaboration.

The organisation has begun to review its activities in relation to the European Partnerships under Horizon Europe [Transforming health and care systems](#) and the [European Open Science Cloud](#) as the EIP on AHA 2018–2020 period came to a close in November 2020.

The EU EYE target of activities was reached in relation to its EIP AHA Commitment entitled [Creating a forum to maximise the integration of research priorities, policies and strategies in eye health](#).

The EU EYE continued to receive direct invitations to high level events as a registered user of the [Health Policy Platform](#) (HPP) of the European Commission (details under [Public consultations, hearings and events](#)).

## Public consultations, hearings and events

Engagement continues with the consultation and decision making process of the EU institutions and its agencies through participation in the following consultations:

- Guidance (v3) for sponsors on how to manage clinical trials during Covid-19 pandemic' (EMA, April);
- IMP distribution to patients [subtopic within the greater consultation on how to manage CTs during COVID] (EMA, April);
- Implications of Covid-19 on methodological aspects of ongoing clinical trials (EMA, April);

- Points to consider on implications of Coronavirus disease 5 (COVID-19) on methodological aspects of ongoing clinical trials (EMA Biostatistics group; April);
- European Strategy for data (EC, May);
- White paper on AI: “Towards an ecosystem for excellence and trust” (EC, June);
- Pharmaceutical Strategy – Timely patient access to affordable medicines: Part I – Roadmap (EC/EMA; September);
- Review of contract and deliverables of ACCESS (vACCine Covid-19 monitoring readinESS) project/consortium (EMA, September);
- Review ACCESS protocols on the effectiveness monitoring of Covid-19 vaccines, one based on test negative design and one on use of electronic health records, with different outcomes (EMA, November);
- Guideline on registry-based studies (EMA, December).

Additional participation by Board members was recorded for the EU survey on Health Data/GDPR which required submission at individual level.

Board members and the EU EYE’s policy advisor, Ioanna Psalti, continued to represent the EU EYE in the following events:

- EMA Joint PCWP HCPWP (March);
- HPP webinar on Covid-19 (April);
- HPP Webinar on Misinformation & disinformation during COVID-19 time (April);
- Pharmaceutical Strategy for Europe (workshop, European Commission; July);
- EXPH The organisation of resilient health and social care following the COVID-19 pandemic (online public hearing (October);
- EMA training day (October);
- EMA public meeting on COVID-19 vaccines (December)

This year, the EU EYE’s efforts were strengthened by additional support from the following experts:

**Public consultations and document review**

Benito Almirante

Anniken Burés Jelstrup

**Representation to high level virtual events**

Anja Tuulonen	1st EU Big Data StakeholderForum (December)
David Wright	

Carlo Cutolo

Line Kessel	Guidance on management of clinical trials during COVID-19 (EMA/EC; May)
Cecilia Martinho	

Aldo Vagge

## International Engagement

**UNESCO.** In July the EU EYE has communicated the specific issues faced by the ophthalmology community with the increasing move to Open Science to the UNESCO Open Science Global consultation with representation in the regional online meeting for Western Europe and North America, followed by extensive written input. The UNESCO Recommendation on Open Science is to be adopted by its 193 Member States in 2021.

**WHO.** The EU EYE has noted that data on eye services (treatments and screening services) may not have been included in the WHO survey on [COVID-19 and NCDs](#). The study was carried out across 155 countries on impact of the outbreak of the disease on service disruption in non-communicable diseases. A query was therefore raised to the WHO Team on Noncommunicable diseases, the WHO Regional Office for Europe and the WHO team working on the draft resolution on Integrated people-centred eye care. The availability of such data remains crucial for the EU monitoring of the impact of COVID-19 on access to eye health services. Any response of the WHO will be further communicated to the relevant units of the European Commission such as the European Observatory on Health Systems and Policies, the Clinical Studies and Manufacturing Taskforce of the EMA.