



European Innovation  
Partnership on Active  
and Healthy Ageing

PARTNER

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# Annual Report

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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 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	Board Member / EURETINA Representative
Massimo Nicolò	Board Member / 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 and have an ongoing 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>BTC</b>	Blood, Tissues & Cells
<b>CLEO</b>	Council of Lived Experience in Ophthalmology
<b>EIP AHA</b>	European Innovation Partnership on Active Healthy Ageing
<b>EMA</b>	European Medicines Agency
<b>ESFRI</b>	European Strategy Forum on Research Infrastructures
<b>EXPH</b>	Expert Panel on Investment in Health
<b>HCP POG</b>	Healthcare Professionals Policy Officer Group
<b>HCPWP</b>	Healthcare Professionals Working Party
<b>HERA</b>	European Health Emergency Preparedness and Response Authority
<b>HPP</b>	Health Policy Platform
<b>MEP</b>	Member of European Parliament
<b>PCWP</b>	Patients and Consumers Working Party
<b>RWD</b>	Real World Data
<b>YIO</b>	Yearbook of International Organisations

## Summary

In 2021 the organisation fulfilled its role under the Observer Status awarded by the EMA and participated in the [HPCWP](#) meetings. The organisation joined the EMA pilot on the HCP POG and provided input on the challenges and priorities in ophthalmology (clinical trials; registries & RWD; pediatric populations; shortages in ocular medicines). The EU EYE registered with the [ESFRI Stakeholders Forum](#) and participation was intensified in key public consultations such as HMA-EMA Data standardisation strategy; General pharmaceutical legislation; HERA; European Health Data Space; BTC Legislation; to name a few. The EU-EYE expanded its presence into the European Parliament by providing panelists for online events and briefing sessions for the MEPs of the TRANSFORM Alliance MEP Interest Group. Key achievements on the patient front were laying the foundations for CLEO (Council of Lived Experience in Ophthalmology) to improve eye patient involvement in policy shaping and research; and the inclusion of chronic eye diseases in the Futurium platform following the folding of the EIP AHA initiative. Individual inquiries on policy, applications and other matters were increased. The website traffic had a 30 % increase in overall visitor numbers compared to 2020.

# EU EYE Activities 2021

## 1. General Organisation

In 2021 the EU EYE enjoyed a stable membership and remained a registered user of the Health Policy Platform (HPP) of the European Commission. The organisation renewed its [entry in the EU Transparency Register](#) and it was also registered with the [Active and Healthy Living in the Digital World](#) hub that operates within the [Futurium](#), a new platform dedicated to civic engagement in EU policies. This platform has integrated the learning from the [EIP AHA](#) initiative and Action Groups: the patient needs with chronic eye diseases of the [Blueprint personas](#)<sup>1</sup>, the policy tool developed by the EIP on AHA stakeholders are now listed in the Futurium after the folding of the EIP on AHA initiative in November 2020. The EUEYE entries in [the Yearbook of International Organisations](#) (YIO)<sup>2</sup> and in the [Horizon2020 Galahad](#) site<sup>3</sup> remained in 2021. In autumn 2021 the EU EYE was registered as stakeholder in the [European Strategy Forum on Research Infrastructures \(ESFRI\) Stakeholders Forum Platform](#); and in the ["Health Workforce Projects Cluster"](#), the ongoing projects evolving from [SEPEN EU Health Workforce network](#), the EU Joint Action on Support for the health workforce planning and forecasting expert network.

Work expanded in laying the foundations for a Council of Lived Experience in Ophthalmology (CLEO). In August 2021 the first EU EYE Working Group (WG-CLEO) was established with the sole purpose to explore how to bring together motivated eye patients and their carers (formal e.g. nurses, charities and informal e.g. families and friends) to improve eye patient involvement in policy shaping and research. The WG-CLEO is to set a loose basis for CLEO, propose inclusion criteria and short-term tasks and provide support when needed with the aspiration that once CLEO is formed, its members will decide an appropriate organisational structure (formal or informal) for further exploration; refine concepts involved; modify what comes out of the pilot and generate solutions that they own before scaling the idea further. It is hoped that CLEO will provide evidence for meaningful policies and regulations by addressing existing gaps in policy for all eye diseases such as lack of awareness about the challenges patients and their carers face within their own healthcare system (available therapies, reimbursement, etc); improve communications with citizens regarding eye health; and

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<sup>1</sup> The Blueprint personas were developed as part of the European Blueprint on Digital Transformation of Health and Care for the Ageing Society by a team of experts with varied backgrounds coordinated by empirica GmbH. The Blueprint is a crosscutting horizontal initiative that reflects the common policy vision of European policy makers, civil society, professional organisations and industry on how innovation can transform health and care provision in our ageing society.

<sup>2</sup>YIO is a comprehensive database of intergovernmental (IGOs) and international non-governmental organizations (INGOs) worldwide; published in English and Chinese

<sup>3</sup> 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.

identify and integrate in research the needs, perspectives and expectations of different groups as far as it is possible (age, ethnic, groups including vulnerable populations such as children, elderly etc).

The EU EYE communications with the greater ophthalmology community continued as in previous year – timely alerts and a series of briefings focussing on emerging concerns of patients, healthcare professionals in ophthalmic practices and researchers. A social media profile (<https://twitter.com/EUEYENews>) was created in line with the EU EYE organisational identity and includes A common EFFORT for A HEALTHIER Europe, a short film on the organisation’s evolution and work since its inception in 2015.

The website has showed a 30 % increase in traffic by new website visitors from 67 countries. The following countries have shown the most prominent % increase when compared to the 2020 figures for the same country:

Turkey (225%)      China (206%);      UK (138 %)      Switzerland (129 %)

## 2      ADVOCACY

In 2021 the advocacy efforts of the EU EYE were strengthened by the following experts in areas other than ophthalmology:

**Jose M. Miró**

Infectious Diseases Service, Hospital Clinic–IDIBAPS, University of Barcelona, Spain

**Benito Almirante Gragera,**

Infectious Diseases Division, Hospital University, Vall d’Hebron, Barcelona, Spain

**Elba Agustí Rovira**

Barcelona Tissue Bank, Barcelona, Spain

The section below lists the various activities per EU institutions and agencies.

### European Medicines Agency

The EU EYE was awarded the Observer Status by the EMA for 2021 and continued to support the EMA in this role with Dominique Brémond–Gignac as the clinical representative to the working meetings of the [HPCWP](#) of the EMA.

The EU EYE also joined the newly formed Healthcare Professionals Policy Officers’ Group ([HCP\\_POG](#)) of EMA, a pilot effort to step up engagement with eligible organisations. This presented an opportunity to increase awareness at regulatory level of the specific challenges of ophthalmology through a series of communications based on collective input of EU EYE Board members and other experts on the topics of:

- Priorities in ophthalmology within the Pharmaceutical Strategy in Europe;

- State of affairs in ophthalmology Clinical Trials;
- Registries & Real World Data with specific references to registries maintained by member societies ([ESCRS registries](#): EUREQUO, ECCTR and EuReCCa; [EGS surgery registry](#));
- Special populations with particular reference to pediatric populations;
- Shortages in ocular medicines across the EU.

## European Parliament

Thanks to the efforts of Marcela Votruba (EVER), the EU EYE expanded its efforts to the European Parliament by joining the [TRANSFORM ALLIANCE MEP Interest Group](#)<sup>4</sup>. The needs of rare ocular diseases were consistently represented in a series of policy events entitled Realising the Potential of Transformative Therapies which run from the launch of the alliance in June 2021 and focussed on optimising cross-border cooperation for equitable access to advanced therapies in November 2021.

## Public consultations, hearings and events

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

### Consultations of the European Commission

- Roadmap/Evaluation & revision of general pharmaceutical legislation;
- European Health Emergency Preparedness and Response Authority;
- EXPH<sup>5</sup> Opinion on Public procurement in healthcare systems;
- EXPH Opinion European solidarity in public health emergencies;
- European Health Data Space;
- Pharmaceutical Strategy – 2nd consultation phase;
- Making liability rules fit for the digital age, AI and the circular economy;
- Priorities, strategy and needs on the EU4Health Annual Work programme 2022;
- Blood, Tissues & Cells (BTC) Legislation/expanded exercise:
  - General Public consultation
  - Targeted consultation to establishments (impact of the reforms on costs).

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<sup>4</sup> The European Alliance for Transformative Therapies (TRANSFORM) is a multi-stakeholder Alliance that connects Members of the European Parliament (MEPs) and policy-makers with patient groups, medical experts and associations, scientists, researchers, industry actors, networks and other relevant stakeholders.

<sup>5</sup> Expert Panel on effective ways of investing in health is an interdisciplinary and independent group established by the European Commission to provide non-binding independent advice on matters related to effective, accessible and resilient health systems.

## Consultations of the European Medicines Agency

- Proposed ICH guideline on Integrating Patient Experience to Better Inform Drug Development;
- Scientific & regulatory challenges experienced by ATMPs;
- Scope of the remote source data verification (rSDV);
- Orphan Maintenance Assessment Reports (OMARs) / Orphan Designation Withdrawal Assessment Reports;
- Training session for patients, consumers and healthcare professionals interested in EMA activities;
- Capturing challenges and priorities for 2021 and beyond

## Representation to virtual events

EMA Joint PCWP-HCPWP

### **D. Brémond-Gignac**

Service d'Ophtalmologie  
enfants et adultes,  
Hôpital Necker-Enfants  
Malades, Paris, France

Data Standards Strategy workshop (EMA)

### **M. Dickmann**

De Universiteitkliniek voor  
Oogheelkunde Maastricht, The  
Netherlands

### **G. Garhöfer**

Department of Clinical  
Pharmacology, Medical  
University Vienna, Austria

ESFRI Roadmap 2021 Launch Event & 1st ESFRI Stakeholders  
Forum Meeting

(Slovenian Presidency of the Council of the EU & [ESFRI](#))

Value Based Healthcare Conference

(Estonian Ministry of Social Affairs)

How can current EU policy initiatives pave the way towards  
treatment optimisation as part of health systems

(MEP Interest Group Biomedical Alliance);

Learnings Initiative for Optimal Use of Big Data (EMA)

[EXPH](#) opinion European solidarity in public health emergencies

IMI impact on patient involvement

### **I. Psalti**

EU EYE Advisor