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Annual Report [2018] - 1st January to 31st December 2018

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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 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

Einar Stefánsson Past President / EURETINA Representative
Leopold Schmetterer Board Member / EVER Representative
Marie-José Tassignon Board Member / ESCRS Representative
José Güell Board Member / EuCornea 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

EIP AHA European Innovation Partnership on Active Healthy Ageing

EMA European Medicines Agency

EOSC European Open Science Cloud (EOSC)

HPP Health Policy Platform

EHSAS European Healthcare Students' Association Summit

EXPH Expert Panel on Investment in Health

MEP Member of European Parliament

STAMP Expert Group on Safe and Timely Access to Medicines for Patients

WHO World Health Organisation

Summary

In 2018 the EU-EYE continued to strengthen its organisational capacity for advocacy work and there was a reorganisation in the Board.

In February the organisation introduced its commitment to the EIP AHA partnership network during the Conference of EIP AHA Partners and reinforced the message for integrated eye care within the B3 Action Group.

An application was filed to the European Medicines Agency (EMA) for consideration for EMA's list of eligible organisations, and the STAMP group has registered the interest of the EU EYE in the work of the repurposing of medicines.

Preparations started 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 (Multiannual Financial Framework investment cluster; Mission approach in research; Evaluation of the legislation on medicines for children and rare diseases.

Positions have been developed on the EOSC, the WHO World Report on Vision, the European Reference Networks and the digitalisation of healthcare.

The redesigned website was launched in May and the monthly production of a tailored e-newsletter was resumed.

Media attention has improved visibility of the EU EYE among the medical world through articles by EuroTimes and SciTech Europa Quarterly.

EU EYE Activities 2018

1 General Organisation

In early 2018 Marie-José Tassignon joined the Board and Ulf Stenevi was succeeded by José Güell.

In September and during the annual Board meeting in Vienna, Austria, Professor Carlo Traverso was voted as President, Professor Paul Rosen as Vice President and Professor Tunde Peto as Treasurer. Jesper Hjortdal remained as Secretary.

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

In May the new website was launched with a new theme and a strengthened narrative of the importance of eye health.

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 downloading of the e-newsletter is monitored for evaluation purposes.

2 Advocacy

The portfolio of activities continued to expand in 2018 with the EU EYE:

- contributing to the "World Report on Vision" of the World Health Organisation (WHO) and calling for fairer assessment of cost-effectiveness and a balance in metrics regarding the impact of eye diseases on the quality of life;

(full response at: http://www.eueye.org/WorldReportVision_Web_21June.pdf)

 working towards the formulation of activities on the sharing of research data in ophthalmology; developing an extensive position paper on the European Open Science Cloud (EOSC) calling for the strengthening of the representation of the medical community within the Open Science Policy Platform to address the diversity in open data needs in healthcare;

(full response at http://portal.eueye.org/EOSC_February2018.pdf)

- filing an application to the European Medicines Agency (EMA) for consideration for EMA's list of eligible organisations;
- registering its interest in the the scientific advise process for the repurposing of medicines with the Unit "Medicines: policy, authorisation and monitoring" of the European Commission and the Expert Group on Safe and Timely Access to Medicines for Patients (STAMP).

The renewed activities of the EU EYE have attracted media interest with two articles appearing on the organisation:

"EXPANDING RESEARCH The EU EYE Alliance is calling for more involvement from experts"; Hanratty Adrian, EuroTimes February 2018;

"An EYE on the Future" SciTech Europa Quarterly 2018, 28, pp 174-175

EIP AHA & HPP

The EIP AHA Commitment entitled <u>Creating a forum to maximise the integration of research priorities</u>, <u>policies and strategies in eye health</u> was published on the online portal of the European Commission on 8 January 2018.

Professor Einar Stefánsson, President of the EU EYE, attended the Conference of Partners of the EIP AHA in 27–28 February 2018. The EU EYE was introduced to the greater EIP AHA partnership network through the presentation of the infographic of its commitment.

The EU EYE participated in the biannual meetings of the B3 Action Group of the EIP AHA in May and November and contributed to the development of the Blueprint on Digital Transformation of Health and Care for the Ageing Society¹. The EU EYE was pleased to see that eye health was integrated among the health and care needs in the Blueprint on Digital Transformation of Health and Care for the Ageing Society, currently under preparation by the EIP AHA.

Dr Ioanna Psalti, external advisor to the EU EYE, has attended the biannual meetings of B3 and the HPP meeting in November.

Public consultations, hearings and events

The organisation has continued its engagement with the consultation and decision making process of the European Commission through participation in the public consultations on:

- -Multiannual Financial Framework investment cluster (EU funds in the area of investment, research & innovation, SMEs and single market) in March;
- -Mission approach in research in April;
- -Evaluation of the legislation on medicines for children and rare diseases in December.

¹ The Blueprint is developed by the Blueprint Partners as part of the EU WE4AHA, a project under the Grant Agreement No. 769705 of the Horizon 2020 Research and Innovation programme. It is a report on the four priority information and communication technology (ICT) topic areas, including recommendations for and solutions to scaling up; and twelve personas representing the health and care needs of focused population groups https://ec.europa.eu/eip/ageing/news/evolution-blueprint_en

The EU EYE continues to engage with the work of the Expert Panel for the investment in Health (EXPH) with attendance at the EXPH hearings and with extensive written responses on:

 "Application of the ERN model in European cross- border healthcare cooperation outside the rare diseases area" (October);
 the EU EYE has called for equity and proactivity to be at the core of the ERNs;
 and, clarity and transparency in any process whether for the enlargement of the ERNs or enrollment of patients.

(full response at: http://www.eueye.org/EXPH ERNs October2018.pdf)

- "Assessing the impact of digital transformation of health services" (November); the EU EYE has called for a holistic health care-specific evaluation model that manages expectations regarding cost-effectiveness through patient-centricity, interoperability and analysis across the entire care pathway and all care settings, and focussing on generating improvements relevant across the patient pathway and the EU policy environment.

(full response at: http://www.eueye.org/EXPH_Digitalisation_November2018.pdf)

A number of key policy events were attended by the following representatives of the EU EYE:

Professor Marie-José Tassignon, Board Member, at the FEAM European Biomedical Policy Forum's annual lecture on "Biomedical and health research: developing a vision for Europe" in March;

Professor Marc Labetoulle, CHU Bicêtre, France at the HPP Thematic Network on Antimicrobial Resistance in March:

Professor Einar Stefánsson, EU EYE President, at the session "Safer and Healthier Work: Facilitating the integration of people with chronic diseases", hosted by the MEP Roberta Metsola of the parliamentary Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs) and organised by the European League Against Rheumatism (EULAR) at the European Parliament in June.

Professor Carlo Traverso, Vice President of the EU EYE, at the session "Interprofessional Education: A way to transform tomorrow's healthcare!", hosted by MEP Lieve Wierinck in the European Parliament and organised by the European Healthcare Students' Association Summit (EHSAS)² in June.

Dr Ioanna Psalti, external advisor to the EU EYE, at the AMR Stakeholder Network meeting in October and at the Dine in the Dark event, hosted by MEP Heinz Becker and organised by the National Council of Blind Ireland (NCBI) in the European Parliament in November.

²EHSAS consists of <u>EPSA</u> (European Pharmaceutical Students´ Association), <u>EMSA</u> (European Medical Students´ Association), <u>EDSA</u> (European Dental Students´ Association) and <u>EFPSA</u> (European Federation of Psychology Students´ Association).