

WAPO activity 2020-21

The World Alliance of Pituitary Organisations (WAPO), are holding their AGM on Saturday 29th May, 2021 when their work over the last 12 months and achievements over this difficult year will be consolidated. Many of the projects highlighted in 2019 were postponed due to Covid-19, and events rescheduled from live to virtual. To support its members, a series of virtual 'global cafés' were held between April and August, in English Spanish and Russian, to enable discussion and provide an on-going presence. Here is a summary of other initiatives:

WAPO Medical Advisory Board

They have four Medical advisors currently in post- Dr Chris Yedinak, Endocrine Nurse; Dr Federico Gatto, Endocrinologist; Prof. Diego Ferone, Consultant Endocrinologist; Dr Debra Katz, Consultant Endocrinologist and Mr Garni Barkhoudarian, Consultant Neurosurgeon. Their role is to support the WAPO activities, support and initiate new activities, support committees in case of questions and have a role in organising webinars and Summits or e-Summits. They will be officially welcomed to WAPO during the AGM.

WAPO Task Force

The WAPO board of directors introduced an initiative to provide member organisations with a problem-solving 'task force' in response to requests for assistance. A small group- four to six people- employed to utilise their collective skills for a particular, time-limited purpose, generally lasting a few months to a year. There will be no restriction to potential problems, and depending on a member's need, a task force can be organized to help solve an issue, provide help for a specific need, or work on a particular project. In addition, members can ask for assistance identify needs within their organisation. The WAPO Board hope establishing a task force will help with communicating and branding activities, promote membership to organisations, improve awareness and assist with patient, stakeholder and physician involvement. Participating member organisations will have access to resources, experience, and expertise that would otherwise not be available.

Patient Organisations

Hope Life, The Gambia joined WAPO in 2020, whilst Acromegaly Organization, Algeria; Cushing's Organization, Spain; Pituitary Foundation, Ireland and Pituitary Foundation, Greece all showed an interest in membership. WAPO currently has members from all over the world, including East and West Europe, North, Central and South America, Africa, South East Asia, and Australasia.

WAPO Summit

Due to the worldwide pandemic, WAPO had to postpone the 5th Summit from March, 2020 in Buenos Aires, Argentina. As a result, an e-Summit was arranged and took place on 3rd October, with over 400 registrants and 130 people attending live sessions. The summit was available in English, Spanish, Russian and Mandarin,

with links to video live sessions also being made available in the four languages after the event. Topics included on the day, which included Q&A sessions were;

- Dealing with psychological issues in the Covid era
- Patients and HCP's: An example of collaboration
- Minor complications of pituitary surgery
- The visual impact of pituitary disorders
- Can adults with pituitary conditions take Growth Hormone?

WAPO Newsletter 'Global Pituitary Voice'

Used to spread knowledge and to keep in contact with our members, Global Voice was established to keep all patient advocacies and third parties up to date with activities in other countries, outcomes of surveys on pituitary conditions, diagnosis and treatment. However, published only once in April 2020, the WAPO Board of Directors made a decision to update the format of the newsletter into a 'Blog', which will be distributed to members when news is available or on a bi-weekly basis.

In addition, close collaboration with Pituitary World News (also a WAPO member) will be improved and articles will be shared via both organizations.

WAPO Awareness activities

Awareness was one of the key priorities of WAPO activities in 2020. WAPO patient organizations were offered a global simultaneous awareness campaign, invited to use the WAPO logo on campaign posters, or have the regional language on the posters.

Awareness campaigns focused on Cushing's Awareness on World Cushing's Day, (8th April), Acromegaly Awareness campaign and for Pituitary Month in October created a poster with all pituitary conditions included. In Lithuania, the poster was adapted into a banner to raise awareness, and featured in the WAPO Blog in November 2020. In addition, the European Society of Endocrinology asked for a poster, in which WAPO had ESE's twitter account inserted, to raise awareness.

Mapping Project

In 2018-19 WAPO performed a mapping project (phase I) as a step towards learning about the members, differences between them, identify needs and plan activities. The project design included a web research, a questionnaire and where possible an interview with WAPO members to collect comparable information. 22 members (including the UK) answered the mapping questionnaire, whilst web-based information provided some insight into areas which did not respond. Key insights included:

- In some countries critical drugs are not available or even not certified.
- Most patient groups are financed by pharmaceuticals and members, and current sources are insufficient
- There are specialists everywhere, but we still do not know about many of them. Patients can be a trusted source of information for other patients.

- We know now the most acute needs of patient groups, and we know who suffers the most.

In 2020, the Mapping Committee worked on an infographic with the outcomes of the 2019 campaign, which was shared via several platforms, e.g. ECE 2020 and WAPO Blog to raise general awareness of the project.

WAPO new Projects September 2020 – December 2021

- WAPO Best Practice & Project Funding- founded in June 2020 to encourage and support member organizations to start with projects, and to support their members (patients and carers). The first grant has been allocated to FAETH Ecuador to make a series of 6 videos in Spanish to support Acromegaly patients in Latin America during the Pituitary Month and Acromegaly Awareness Day. Other South American organisations were able to share these resources for the benefit of their own members.
- Mapping project 2- began January, 2021 to update earlier information and interview new members to provide input on the situation in their region, as well as information on their patient advocacy, community, etc.
- WAPO Task Force- a broad spectrum of support to patient advocacies, e.g. training, support with substandard medications or government, knowledge, project ideas and/or else, the first initiative being training.

WAPO Partnerships and Relations

- AdrenalNET- an online community for adrenal diseases, mainly focusing on European patient organizations. WAPO liaised with them in connection with a new Cushing's brochure, so it was made available in Spanish having been translated by the Spanish interpreter from the WAPO summit.
- The European Patients' Academy (EUPATI)- a pan-European project implemented as a public-private partnership by a collaborative multi-stakeholder consortium from the pharmaceutical industry, academia, not-for-profit, and patient organizations. WAPO used social media to highlight the EUPATI 'Open Classroom', and aims to provide financial support to those WAPO members who wish to undertake the Patient Expert course and obtain their certificate.
- European Society of Endocrinology (ESE) / European Congress of Endocrinology (ECE)- WAPO attended the on-line Conference where they shared the infographic on the Mapping Project and informed participants about the eSummit in October, 2020.
- EURORDIS- WAPO joined several online meetings in 2020.

- ENDO-ERN- the endocrinology section of the European Reference Centres. WAPO follows all news from ENDO-ERN (via Newsletter, LinkedIn, etc
- FindMeCure- an organization which links the clinical research industry and people looking for a new, alternative treatment.
- Federation of International Nurses in Endocrinology (F.I.N.E)- members since 2018, WAPO works closely with Dr Chris Yedinack to ensure all medical information on WAPO website is accurate and up to date.
- GAFPA (Global access for Patient Advocacy) and LAPA (Latin Patient Academy)- WAPO Board member is an active member of both organisations.
- Patient Focused Medicines Development (PFMD) – WAPO Board member has been active in two core workgroups focusing on the publication of lay-summaries and an information leaflet.
- Pituitary World News- co-editor is a WAPO Board member, sharing articles, podcasts, and educational videos throughout 2020. PWN launched its Spanish platform, Pituitary World News en Español, in July of 2020, which will also support WAPO member organizations.
- International Society of Endocrinology (ISE)-An Education Trainer presented on: 'Patients and HCPs: An Example of Collaboration' during the WAPO eSummit
- Oxford PharmaGenesis- liaison continues
- Rare Diseases International (RDI)- In November 2020 WAPO was invited to a call on the WHO Collaborative Global Network for Rare Diseases, to enable International Federations to share their perspective and experience on the global context for their specific rare disease area.

Finances

The annual WAPO Membership Fee is €35