



WAPO Activity Report 2018

WORLD ALLIANCE OF PITUITARY ORGANIZATIONS

WAPO 2018 Activity Report

Introduction

WAPO activities in 2018 were focused on the priorities set at the Summit: internal and external communications, awareness campaigns, best practice sharing, international travel letter, mapping project and Summit 2019. WAPO board members and several volunteers were active and successful.

WAPO is still a young organization, and yet we have already proved our ability to collaborate, to achieve interesting results. And to attract new volunteers and partners to work together for mutual benefit.

We are looking forward to the Summit 2019, WAPO's flagship event, where we will collaborate with the European Society of Endocrinology (ESE) during the European Congress for Endocrinology (ECE2019) in Lyon, France. It will also be a great opportunity to share the outcome of the 'WAPO Mapping Project' with our member organizations, partners and ECE2019 participants. During the Summit, the targets for 2020 will be set.

WAPO Board of Directors

The WAPO Board of Directors consisted of

Mr. Andrei Andrusov	Chair
Mrs. Sheila Khawaja	Vice-Chair
Mr. Ernest Lundu	Treasurer
Mrs. Muriël Marks-de Korver	Executive Director/Secretary
Mrs. Malini Raj	Board member
Mrs. Sue Kozij	Board member
Mrs. Sandra Mesri	Board member
Mr. Weiqiang Zhan	Board member
Mrs. Sonja Durinck	Board member

The WAPO Board has met 'in person' during the Board meeting of April 22nd, 2018. From there, based on the GoToMeeting teleconference service, there were 24 Board meetings which - on average - lasted for 72 minutes and with 5 - 8 participating Board members from all over the world. The meetings usually started at 8pm Central European Time). This is the optimal time given the Board members live in different time zones: Argentina: -4hrs | Australia: + 8/9 hrs and + 9/10 hrs | Canada: -7hrs | Italy: 0 hrs | the Netherlands: 0 hrs | Russia: +2 hrs | South Africa: +1 hr | China: +6 hrs.

Other committees also met during the year, also on other platforms.

Finances

During 2018 Ernest Lundu took over the role of Treasurer from Malini Raj, and took care of overlooking the WAPO finances in collaboration with Muriël Marks and Andrei Andrusov. WAPO also transferred the accountancy to Trajectum, Mr. Theo Nout as of January 1st, 2018.

WAPO has also started to collect a Membership Fee for Full Member Organizations as of January 1, 2018, as approved during the AGM on May 14, 2017.

The annual Membership Fee for 2018 was fixed at €35 per patient organization.

WAPO Board activities

During the Board meeting of May 14, 2017, the WAPO Board decided to create committees, that were also active in 2018.

WAPO Board created the following committees:

- Finance Committee
- Fundraising & PR Committee
- Summit Committee
- Awareness Committee
- Membership Committee
- Website, Social Media and Technology Committee
- Communications Committee including:
 - Newsletter team
 - Best Practices team
 - Medical Committee team
 - Maps team
 - Surveys team
 - Webinar team
- Mentorship Committee

Newsletter 'Global Pituitary Voice'

[The WAPO Newsletter](#) 'Global Pituitary Voice' appeared 3 times in 2018. The content varied, but always contained a 'Chair's foreword, patient story and doctors' article or projects by WAPO members and a Calendar with pituitary related events. WAPO collaborated with Pituitary World News (WAPO member) to share information for mutual interest.



WAPO Awareness Activities

Awareness is one of the key priorities of WAPO activities since the Summit 2018.

Acromegaly Awareness campaign

WAPO ran a campaign during the 'World Acromegaly Awareness Day' on the 1st of November 2018. The campaign was shared by email to all WAPO member organizations and on Facebook. Many WAPO member organizations shared the poster of the campaign during these days and asked their members to paint their face, hands or feet with colours to show their grown body parts. We have received a lot of pictures by patient organizations via email or Facebook.

We consider the campaign a considerable success.



'Pituitary Awareness WAPO' Pin

In order to increase the awareness for pituitary diseases, rather than per disease, the WAPO Board of Directors created the 'WAPO Pituitary Awareness' pin. The 1300 pins were made by a company in Argentina and at the end of 2018, there were 500 pieces left to use in 2019. During the WAPO Summit 2018 the WAPO member organizations received several pins, as well as the speakers and sponsors, and we gave away a large number at our stand during the ECE2018 in Barcelona.



'WAPO International Travel letter'

WAPO searched for a way to support NGOs and individual patients with pituitary diseases while travelling. The outcome was a document which patients could download and take along to their doctor, where the physician could fill in all information on the disease, medication and treatment. Another part of the travel letters is a page with 'tips and tricks' while travelling. All can be downloaded for free from the WAPO website.

The documents were professionally translated, which was made possible thanks to financial support of Ipsen, and in kind support by HRA and Chiasma.

As of December 31, 2018 we had the following languages available: Arabic, Chinese (simplified), English, French, German, Hebrew, Italian and all were uploaded after an article in the WAPO Newsletter on to the WAPO website in the first couple of months of 2019.

MAPPING

WAPO has made efforts to start the 'WAPO Mapping Project'. From November 2018 the actual project started. Approval of funding and Christmas holidays delayed the project slightly and we had to stretch the period of collecting information for the project till mid January. The interviews and collecting all data as well as the end-reporting was carried out by Main Consultancy in Argentina.

The project goals were:

1. Receive and update information from WAPO Member organizations, receive additional information per country, etc.;
2. Receive information to create an overview of hospitals for treatment per country;
3. Receive information on medication availability per country.

This project was made possible with financial support of Pfizer.

SUMMIT

In 2018 the Summit Team included 4 Board members, who organized 21 teleconferences to organize the summit 2018 and started with 2019, which meetings on average lasted 55 minutes.

The third WAPO Summit was organized from April 20 - 22, 2018 at the Crowne Plaza East Venice in Quarto d'Altino, Italy.

Patient advocates, speakers and sponsors were invited to join the Friday afternoon program from 3pm CEST. At the start, Andrei Andrusov (Chairman) and Kathy Redmond (moderator, Redmond Consulting) welcomed all guests present, and then asked everyone to introduce themselves. The program went on with several presentations of 'best practices' - successful projects by member organizations - given by patient advocates.

Fabio Neri (Mesa_Lab) held an introduction on Twitter and Social Media, to support the use of the 'Social Media Wall', where people could share their Twitter messages and/or pictures while participating at the Summit.

In the evening all attendees joined the 'Welcome dinner' at the hotel.

On Saturday, April 21st, 2018, WAPO organized a program with several presentations by guest speakers. The following guest speakers were present and spoke on interesting topics:

- o Optimizing pituitary hormone replacement by Prof. Richard Ross (Sheffield University - UK)
- o Pituitary centres of reference by Dr. Felipe Casanueva (University Santiago de Compostela, Spain)
- o Importance of the multidisciplinary team (Pituitary Unit) by Prof. Federico Gatto (University of Genoa, Italy)
- o Introduction to 'Mindfulness' by Dr. Michelle Zandvoort (UK)

All presentations were followed by Q&A sessions, to give the audience a platform to ask their questions.

In the evening, most participants joined the dinner at a restaurant, where everyone enjoyed the food and shared experiences, stories, etc.

Summit Poster contest

The patient advocates brought along 22 posters on a 'best practice' and all participants could vote on each poster. On Sunday morning, the votes were counted and Sheila Khawaja presented the first and second prize winners:

1. COAT, represented by Vivian Chang (Taiwan) won the poster contest.

The organization received a 'waiver of the attendance fee of €135 at the Summit in 2019' and a 'Certificate of Appreciation',

2. The Pituitary Foundation UK/Ireland, represented by Niall Cavanagh, won the second prize, a 'waiver of the Membership Fee 2018 of €35' and a 'Certificate of Appreciation'.

Annual General Meeting

The Annual General Meeting (AGM) was held on Sunday, April 22nd, 2018, where only full member organizations were allowed to join. Each organization was eligible for one vote. In the 2018 AGM, full members voted several times, e.g. on the election of a new Director.

Summit & AGM - General information

The 2018 Summit was attended by 24 WAPO Full Member patient organizations with a total of 30 patient advocates. There were 5 guest speakers, 7 industry representatives ('observers' only) and 2 interpreters (English-Spanish). Eric Kozij supported the WAPO Summit with filming and hands-on activities during the full 3 days.

During the Summit we showed 2 WAPO Summit banners including the logos of the supporting pharma industry sponsors. Furthermore, WAPO presented three signs to take pictures with: the word '#WAPO2018', the 'WAPO Pituitary Awareness pin' and the word 'Pituitary'.

The WAPO Summit was made possible with financial and in-kind support of the following pharmaceutical companies: Pfizer, Novartis, Ipsen, Chiasma, HRA and StrongBridge Bio. On behalf of the WAPO Board of Directors and all WAPO Full Members, we thank them for their trust in WAPO and would like to continue our collaboration in 2019.

WAPO Member Organizations

In 2018 WAPO welcomed one new WAPO Member Organization: 'Acromégaly .. pas seulement', based in France.

WAPO received 7 requests by individual patients to become a WAPO member, but none of them were interested to start their own organization. They were advised (in detail) to contact a national patient organization in their country or a nearby country.

In 2018 WAPO received 2 requests by member organizations regarding the availability of medicines, for which we contacted the pharmaceutical companies involved. Both situations were solved with their help.

WAPO Medical Advisory Board

In 2018 WAPO established a Medical Advisory Board. The goal of the MAB is to connect to HCPs and ask after their advice in case there are medical questions by WAPO Full Member organizations and to have at least three medical advisors in several fields of interest in the treatment of a pituitary patient.

Both Ass.Prof. Diego Ferone and Ass.Prof. Chris Yedinak have accepted the WAPO invitation to join the MAB.

WAPO Partnerships and Relations

EUPATI

The European Patients' Academy (EUPATI) is 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 organisations. EUPATI has a training facility on medicines development, clinical trials, medicines regulations, health technology assessment. Additionally, EUPATI offers and maintains the Toolbox on Medicine Development, and coordinates a network of national platforms for patient advocates. WAPO is receiving their newsletter and updates by email frequently.

European Society of Endocrinology (ESE) / European Congress of Endocrinology (ECE)

WAPO was represented in May at the ECE2018 in Barcelona by Sheila Khawaja and Muriël Marks with a table stand where information, newsletters, Dutch peppermints and WAPO Pituitary Awareness pins were shared. Physicians and endocrine nurses frequently asked after WAPO activities and over 45 persons left their contact details (including email), to

receive the WAPO Newsletter.

During ECE2018 Muriël and Sheila were invited to 2 meetings with ESE directors and other patient advocacies, and a separate meeting was organized to discuss a possible collaboration at the ECE2019 with the ESE Nurses. The outcome for WAPO was to present a tentative program by end of July 2018.

The WAPO Summit Team 2019 worked from June 2018 onwards to present a program for the Summit 2019, contacted speakers and presented the program in July 2018 to ESE Nurses. From there, frequent teleconferences were held to discuss the topics, program and possibilities. In October 2018 both parties agreed to work together in 2019.

EURORDIS

EURORDIS is a non-profit alliance of over 700 rare disease patient organizations from more than 60 countries that work together to improve the lives of the 30 million people living with a rare disease in Europe.

By connecting patients, families and patient groups, as well as by bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

WAPO received their newsletters, mailings and paid an annual membership fee.

ENDO-ERN

ENDO-ERN is about the endocrinology section of the European Reference Centers. Some of WAPO members are involved in the ENDO-ERN. WAPO receives their regular Newsletter and shares interesting updates with WAPO member organizations via mail and Facebook.

FindMeCure

WAPO got in contact with FindMeCure in 2017 and became partners shortly after.

FindMeCure is an organization which links the clinical research industry and the people looking for a new, alternative treatment.

On the WAPO website a widget has been installed, where patients can search for new clinical trials on pituitary and adrenal diseases globally.

Federation of International Nurses in Endocrinology (F.I.N.E)

WAPO is a member of F.I.N.E. since 2018 and worked together to receive input from F.I.N.E. members for the WAPO International Travel letter.

GafPA (Global access for Patient Advocacy)

In 2018 WAPO participated in all three meetings of GAFPA (Global Access For Patient Advocates) which took place in San Pablo - Brasil, Miami - USA and Lima - Peru. The main topic was 'bio-similars'.

Membership of GafPA is free. Participants are leaders from Latin American regional patient organizations.

Patient Focused Medicines Development - PFMD

Since 2017, WAPO and PFMD are working together. We have attended several meetings and teleconferences, which are for the benefit of the patient.

Their 'Pledge' campaign is shared through the WAPO social media, and we're looking for a way to follow-up on this in the Summit 2019.

We haven't completed the undersigning of the 'Memorandum of Understanding' but this will happen early February 2019.

Pituitary World News

Since PWN is a WAPO Full member organization, we share mutual interesting articles via social media. One of their Directors, J. Faccinetti also shared his input in several 'Communications Committee' teleconference.

They even have a WAPO section on their website, where the WAPO Pituitary Global Voice is shared as well as WAPO related activities or awareness campaigns.

Rare Disease International

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases, and related to Eurordis.

They bring together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

Andrei Andrusov visited their annual meeting in Vienna, Austria.

WAPO receives their newsletter and mailings.

Oxford PharmaGenesis

The collaboration with Oxford PharmaGenesis started in 2016 and went on in 2017 and 2018. We had several teleconferences on the awareness campaign for Acromegaly in 2018.

INTERNATIONAL MEETINGS

WAPO representatives have attended several international congresses to increase WAPO's visibility and meet with possible new sponsors, interesting third parties, etc.

Phar East - Asia's Pharma and Biotech Festival - Singapore - early March 2018

WAPO was invited to attend the conference which focussed on exploring 11 pharma areas in Asia: immunotherapy, vaccines, precision medicine, cell & gene therapy, biodata, orphan drugs, partnering, commercialisation & market access, antibodies, biosimilars and biotech innovation. Attendees included big pharma and biotech, regulators and payers, solution providers and technology leaders.

It was an opportunity for WAPO to attend sessions and build new relationships, with a view to get more presence and connections in the Asia Pacific Region.

Malini Raj was invited to facilitate a Roundtable discussion and interview prior to the event.

The topic for the Roundtable was "Bring it Together – Patient, Pharma, Hospital, Government in Drug Development" and highlighted a consistent view of the need of a strong patient voice when developing drugs or treatment options.

ECE 2018 - Barcelona, Spain - May 2018

WAPO was invited to speak at the Nurses' pre-congress event day and Sheila Khawaja spoke on 'Raising awareness of diabetes complications in patients with endocrine conditions'. The talk was well-received and raised numerous questions from the audience.

World Drug Safety 2018 - Amsterdam, The Netherlands - September 2018

WAPO is deeply interested in clinical trials to understand the details of a product life-cycle, its safety and to ensure that patient-centricity is taken into consideration by all industry players. At the Amsterdam conference, WAPO was the only patient organization attending the event: of the 60+ activities and talks, only 2 roundtable sessions dealt with patient safety or patient-centricity. WAPO was invited to speak and perhaps even help organize an event involving more patients for the 2019 edition.

EURORDIS 27th ERTC 2018 - Barcelona, Spain - October

The main topics in this session were 'Patient engagement in product life-cycle' and 'Community Advisory Boards (CABs)': WAPO attended the event to learn how EURORDIS and the industry intended to increase patient engagement. The PARADIGM project and its benefits were highlighted; the second most relevant topic was the CABs (explanation of the project with case study examples) with an invitation to any other patient organizations to contact EURORDIS and evaluate the feasibility for WAPO as a global alliance organization (CABs seemed to be more appropriate for national organizations).

PFMD-ENVISION workshop on Publication of Lay Summaries (PLS) - London, UK - November

WAPO's vice chair, Sheila Khawaja was invited by PFMD to co-chair the task-force for the 1.5 day workshop event which involved not only pharma stakeholders, but also patient organizations, journal publishers, as well as regulatory and compliance representatives. Ultimately, the purpose is to create a Patient Engagement Quality Guide that can be used by all stakeholders to ensure the best dissemination of medical research, using lay terms and offering maximum accessibility. As a follow-up the workshop will also create a toolkit to ensure patients are included in this phase of drug development. Work groups will be created on different aspects and WAPO will have an active role in 2019.

WAPO CONTACT INFORMATION

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