



WAPO Activity Report 2020

WORLD ALLIANCE OF PITUITARY ORGANIZATIONS

WAPO 2020 Activity Report

Introduction

The WAPO activities in 2020 were heavily influenced by the COVID-19 pandemic, which had a huge influence on patients, treatment and in some cases the availability of medications! Priorities and action points set in the 2019 Summit were postponed or cancelled due to the situation patient organizations had to deal with. Many events where WAPO directors would participate in, were rescheduled from live into virtual or even cancelled. To support patient advocacies, new ideas and activities came up and the Board tried to reach out to member organizations in a supportive way. An example are the 'Global Café' sessions (April till August) in English, Spanish and Russian.

We hope 2021 will be a year to move forwards again, certainly when the vaccines will be available, and where we can meet again in October with our members!

The WAPO Board of Directors,
December 2020

WAPO Board of Directors

The Board consists of the following members, who were (re-)elected for a period of 3 years in 2019:

Mr. Andrei Andrusov	Chair / Treasurer
Mrs. Sheila Khawaja	Vice-Chair
Mrs. Muriël Marks	Executive Director / Secretary
Mrs. Susan Kozij	Board member
Mrs. Sandra Mesri	Board member
Mr. Jorge Faccinetti	Board member

WAPO Board activities

Between January 1 - December 31, 2020, the WAPO Board of Directors met via GoToMeeting and Teams 24 times in Board meetings. In 85% of the meetings, all board members were attending and meetings lasted for 60-70 minutes.

The following WAPO Board Committees - established in 2017 - are still active (see below):

- Finance Committee
- Summit Committee
- Awareness & PR Committee
- Membership Committee
- IT Committee
- Communications Committee including:
 - Internal Communications

- Best Practices & Projects Team
- TaskForce Team
- Mapping Team

- External Communications
 - Newsletter/BlogTeam
 - Awareness Team

WAPO Member Organizations

Patient organizations in 2020:

WAPO has welcomed a new member organization in 2020:

- Hope Life, The Gambia, October 2020

Pending organizations in 2020:

Patient organizations who have interest in a WAPO Membership, but are not yet ready to join:

- Acromegaly organization, Algeria
- Cushing's organization, Spain
- Pituitary foundation, Ireland
- Pituitary foundation, Greece

SUMMIT

Due to the worldwide pandemic, WAPO had to postpone the 5th celebration Summit from March 20-22, 2020 to 3-5 October in Buenos Aires, Argentina. We were very glad the Novotel Buenos Aires did understand the situation and supported us here.

On June 30, 2020 we made a final decision to cancel the Summit, and to organize a virtual eSummit 2020.

Several WAPO sponsors supported us with suggestions, and we found in Cello Health Communications a great supportive company to organize an eSummit, in four languages (English - Spanish – Russian – Mandarin).

Speakers were invited, and were supported by Cello Health Communications, while pre-recording their presentations. During the live meeting, all speakers were present, to answer questions in the Q&A sessions and the Roundtable session.

We were very proud Chi Pakarinen (The Synergist/PFMD) accepted to facilitate the event.

We were very impressed with >400 subscribers, while during the eSummit sessions around 130 people attended. Afterwards, we sent out a Blog (via Mailchimp), including the links to the website where videos of all presentations were shared in four languages (English, Russian, Spanish and Mandarin).

The event was made possible with support of Pfizer, Ipsen, Novartis, HRA Rare Diseases, Recordati Rare Diseases, Chiasma, Crinetics and StrongBridge Bio.

WAPO eSummit Program:

- 15:00 Welcome
- 15:10 **Dealing with psychological issues in the COVID era**
By Alicia Santos and Eugenia Resmini (Hospital Sant Pau and CIBERER747, Spain)
- 15:30 **Patients and HCPs: An Example of Collaboration**
By Pamela Funes (International Society of Endocrinology, Netherlands)
- 15:50 **Q&A**

- 16:20 **Minor complications of pituitary surgery**
By Garni Barkhoudarian (Neuro-Pacific Institute, USA)
- 16:40 **The visual impact of pituitary disorders**
By Lucas Viana (FLENI hospital, Argentina)
- 17:00 **Q&A**

- 17:30 **Can adults with Pituitary Disorders take Growth Hormone?**
By Debora Katz (FLENI hospital, Argentina)
- 17:50 **Roundtable session / questions to speakers**
By Chi Pakarinen (PFMD/The Synergist, Belgium)
- 18:30 Closure

TELEMEDICINE

1. It can be easy and convenient having online medical assessment while staying at home
2. Online visits are not the same as in-person visits
3. Online medical training and education
4. Empowerment of patients
5. Telemedicine can overcome geographic barriers to healthcare (can increase efficiency of care delivery, reduce expenses of caring for patients or transporting to another location, and can even keep patients out of the hospital)

Images from Free-Photos in Pixabay

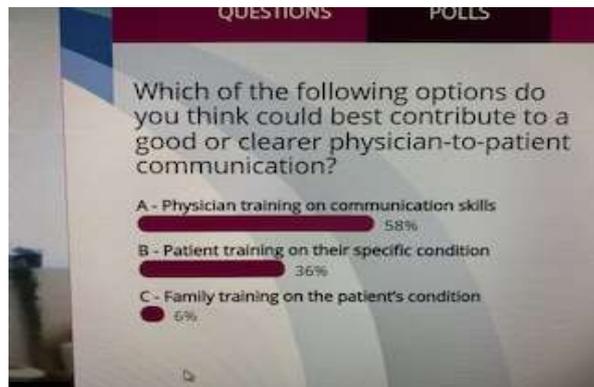
World Health Organization

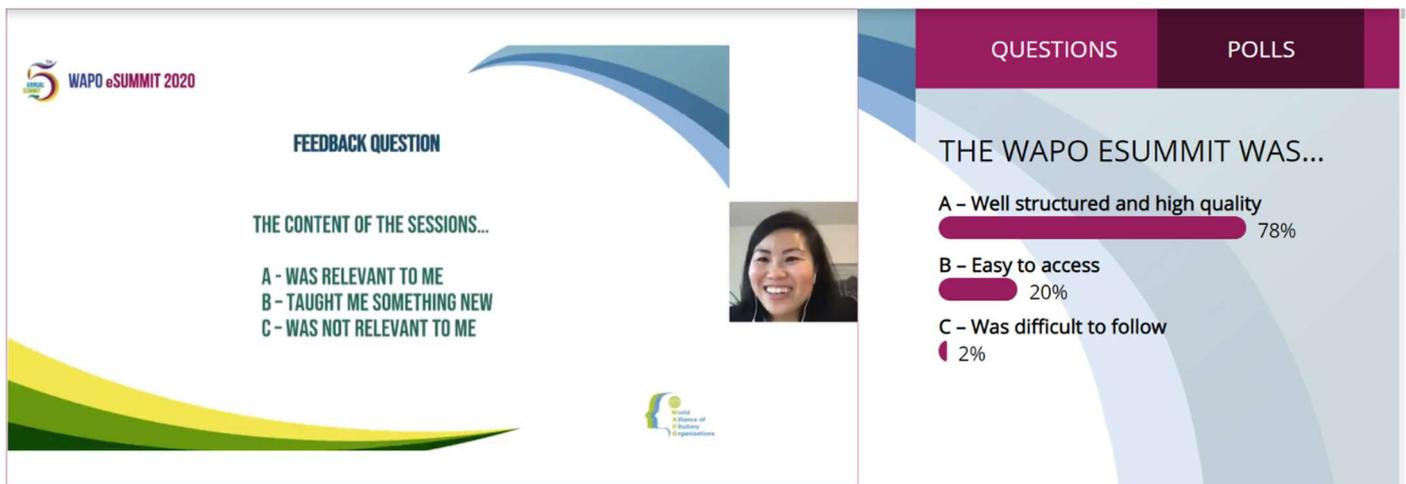
EMOTIONS ARE ADAPTATIVE

Please, listen to me

Image: <https://pixabay.com/stock/photos/only-emotion-ia-enqpbz-237920/>
Image from Gino Cresciani in Pixabay

World Health Organization





Comments received after eSummit

- *'Well done team ! Great eSummit!'* (patient advocate)

(patient advocate)

- *'There were many very interesting subjects and all the lectures were easy to follow. WAPO, what an excellent eSUMMIT!!!'* (patient advocate)

- *'This message is to congratulate WAPO for the very straightforward virtual meeting. It was really high quality and well-structured. For me, it was a pleasure to join.'* (industry)

- *'This event is yet another milestone for us/WAPO.'* (patient advocate)

- *'I take the opportunity to congratulate the WAPO team for the WAPO Summit last Saturday!*

The program was nicely done with a great mix of scientific education sessions and capability building ones and everyone had a chance to learn something!

Sharing your "best practice" of collaboration with Scientific society was of great interest to me as well as the insightful discussion and poll on the "enablers" of a good physician-to-patient communication .

I was pleased to hear that 400 participants from 43 countries registered to the Summit. Well done!!!' (industry)

'Congratulations on the success of the Summit! Despite being virtual, you made the most out of the event for WAPO – thanks for all the hard work which went to making that happen.' (industry)

- *'I've learned sooo much today'* (patient)

Annual General Meeting

We invited all members to vote by Proxy on several topics, due to cancellation of the WAPO Annual General Meeting (included in the WAPO Summit). 22 Full Member organizations voted by 'PROXY' via Survey Monkey. During a 'Global Café', the WAPO Chair presented the figures and patient advocates could ask questions.

WAPO Newsletter 'Global Pituitary Voice'

The WAPO Newsletter 'Global Pituitary Voice' is used to spread knowledge and to keep in contact with our members. It keeps all patient advocacies and third parties up to date with activities in other countries, outcomes of surveys on pituitary conditions, diagnosis and treatment. In 2020 the 'Global Pituitary Voice' appeared only once, early April 2020.

In February 2020 the WAPO Board of Directors made a decision to update the format of the newsletter into a 'Blog', which we will distribute when news are available or on a bi-weekly basis.

Only mailing list subscribers will receive the Blog, which is also visible on the WAPO website in 'Blog'. Promotion via social media will also support the blog posts.

Collaboration with Pituitary World News (also a WAPO member) will be improved and articles will be shared via both organizations.

WAPO Awareness Activities

Awareness is one of the key priorities of WAPO activities in 2020. WAPO patient organizations were offered a global simultaneous awareness campaign. Due to other priorities, we choose to repeat the 2019 campaigns. Again WAPO offered patient advocacies to have their logo on the posters, or have the regional language on the posters. Especially for Pituitary Month – October - we created a poster with all pituitary conditions included.

Cushings' Awareness campaign

WAPO ran a campaign during the 'World Cushings' Day' on April 8, 2020.

The Board decided to run the same campaign again, to save money. The campaign poster (in English and Spanish) was shared by email to all WAPO member organizations and on WAPO's Facebook general page and the WAPO closed FB Forum Group. Again the campaign was successful, and over 475 people looked at the Awareness poster.



In 2021 a new campaign will be designed.

Acromegaly Awareness campaign

For 2020 the WAPO Board decided to design a new campaign to raise awareness on all pituitary disorders in October, during 'Pituitary Month'.

Again we offered members to adjust the text in their regional language and insert their logo. Four patient advocacies asked for this and two organizations managed to do this by themselves and three organizations combined their campaign in the regional language.

#PITUITARY MONTH

EIGHT PITUITARY DISEASES, ONE CAUSE

World Alliance of Pituitary Organizations
WWW.WAPO.ORG

- ACROMEGALY
- ADULT GROWTH HORMONE DEFICIENCY
- CRANIOPHARYNGIOMA
- CUSHING'S DISEASE | HYPERCORTISOLISM
- DIABETES INSIPIDUS
- HYPER/HYPOPITUITARISM
- NON-FUNCTIONAL PITUITARY TUMORS
- PROLACTINOMA

For the 2020 Acromegaly Awareness Day we re-used the 2019 'International Acromegaly Awareness Day' poster on November 1, 2020.

In Lithuania, Dr. Knispelis adapted the poster into a banner to raise awareness (see WAPO Blog – November 13, 2020). And even the European Society of Endocrinology asked for a poster, in which WAPO had ESE's twitter account inserted, to raise awareness! Member and partner organizations shared the campaign, which was therefore very successful once again.

MAPPING / DATA

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

In 2018-19 WAPO has performed a mapping project (phase I) as a step towards learning about the members to better serve them

PROJECT DESIGN: A web research + a questionnaire + an interview with WAPO members to collect comparable information

Project objectives:

- Get the big picture
- Learn about the differences
- Identify needs
- Plan activities

The questionnaire

- Country statistics including prevalence
- Patient's problems in the country
- Best practices of patient advocacy
- Fundraising practices
- Specific advocacy team expertise
- Needs assessment
- Drugs available in the country
- Medical experts in the country

22 WAPO members answered the total questionnaire
Caps filled with web information where possible

Key insights

- 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.

Sources of income of pituitary patient groups

Source	Percentage
Pharma	48%
Members	30%
Government	23%
No budget	21%
Other	62%

Financial support (especially for emerging countries)

- Awareness information and networking resources
- Professional management / training in management / mentorship programs in:
 - Volunteers and community management
 - Fundraising
 - Database management
 - Legal issues and policy making
 - Creation of international guidelines

WAPO PROJECTS September 2020 – December 2021 (NEW)

1. WAPO Best Practice & Project Funding

The WAPO Best Practice & Project Funding Committee was founded in June 2020 to encourage and support member organizations to start with projects, and to support their members (patients & carers).

The invited committee members were part of WAPO member organizations, as they had broad experience in organizing projects and were interested in supporting other WAPO Member organizations with their projects.

The Best Practice & Project Funding support is made possible with several donations (total sum €5,000).

Per September 1, 2020, member organizations were invited to send in their project description, after which they would meet with 3 committee members, who would 1. discuss the project, 2. approve financial support and 3. support the project during all stages (idea – product – evaluation – presentation).

From the start, WAPO received four requests for support, where only one project was granted. Other projects didn't meet the requirements and one project was defined for health care professionals.

With the funding of €500, FAETH Ecuador made a series of 6 videos in Spanish to support Acromegaly patients in Latin America during the Pituitary Month and Acromegaly Awareness Day. Other organizations shared these videos as well.

2. WAPO Mapping

In Q3-2020 WAPO began preparations for the second Mapping Project (Mapping II) 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.

The Mapping Project_II will start in January 2021.

The Mapping_II project is made possible with support of Recordati Rare Diseases.

3. WAPO TaskForce

In September 2020, the WAPO Board started the TaskForce Committee, meant to have a broad spectrum of support to patient advocacies, e.g. training, support with substandard medications or government, knowledge, project ideas and/or else.

The activities in the 'Best Practice & Project Finding' committee are in close harmony with the WAPO TaskForce committee.

The first project we will offer is '**Training**':

In December all WAPO member organizations were offered to join an online training via the 'EUPATI Open Classroom', which includes several modules on specific topics in English. WAPO will also start a support group, to discuss and support the information, then make sure everyone can receive their course certificates. WAPO financial support is limited up to 2 persons per organization and up to a certain amount. The TaskForce project is made possible thanks to the support of Recordati Rare Diseases.

WAPO Partnerships and Relations

WAPO is in partnership with most of the global players impacting patient's lives. Most of these partnerships create value for WAPO members through interaction with knowledge sharing, collaboration and/or opportunities for our members. Most partners have organized virtual conferences, events, where WAPO was also represented. Of course WAPO intends to increase its collaborations in 2021.

ADRENALNET

AdrenalNET is an online community for adrenal diseases, mainly focusing on European patient organizations.

Recently they finished their new brochure on 'Cushing's'. The WAPO Board discussed to have the brochure translated in Spanish and add the WAPO logo in the Spanish version of the brochure, which was approved by AdrenalNET. Afterwards, WAPO requested one of the Spanish interpreters at the eSummit to translate it, and WAPO took care of the finances (translation). Now the brochure is in the last phases of modifications followed by a final check by a Spanish Endocrinologist.

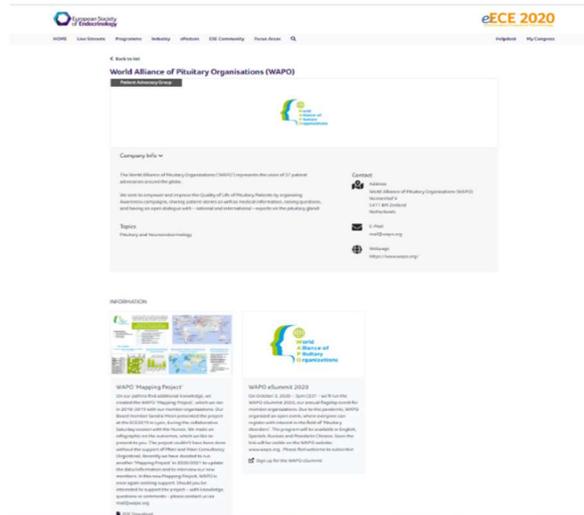
EUPATI

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 organizations.

In the last quarter of 2020, EUPATI launched the 'EUPATI Open Classroom' to enable patient advocates around the world follow the online course. Participants register for free and if they wish to receive a certificate as an 'EUPATI Patient Expert', the participant needs to complete assessments at the end of each 'session group' (this is the paid version). WAPO announced the course via social media and aims to provide financial support to those WAPO members who take the paid course and obtain their certificate. This falls within the 'Training' section of the WAPO Taskforce.

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

Like other organizations, ESE also organized an online eECE 2020, for which WAPO received 2 free passes and the possibility to share information on the Exhibition platform during the congress. WAPO shared the infographic on the Mapping Project and informed participants about the eSummit on October 3, 2020



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.

Interesting news is shared with WAPO members through the WAPO closed FB Forum Group. WAPO also joined several online meetings in 2020.

ENDO-ERN

ENDO-ERN is the endocrinology section of the European Reference Centers. WAPO follows all news from ENDO-ERN (via Newsletter, LinkedIN, etc).

FindMeCure

WAPO contacted FindMeCure in 2017. FindMeCure is an organization which links the clinical research industry and people looking for a new, alternative treatment. Since then we signed an agreement to become partners. During 2020 contact was on a low scale, although we keep following new developments.

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

WAPO is a member of F.I.N.E. since 2018.

Prof. Ass. Chris Yedinak organized a survey on 'Adrenal Insufficiency in relation to Covid-19' era, which was supported by WAPO (input, check and share).

Furthermore, Chris Yedinak supports WAPO by ensuring that medical information on our website is updated, as well as making sure videos are understandable to those who do not feel comfortable reading highly medical information.

Last but not least, WAPO (Muriël Marks) recently joined the ACT community, where – upon invitation - patient organizations related to adrenal insufficiency are organized and collaborate.

GAFPA (Global access for Patient Advocacy)

Sandra Mesri (Argentina) is an active member of the Academy since 2018.

The membership of GafPA is only for patient advocacy leaders, and upon personal invitation.

LAPA (Latin Patient Academy)

Sandra Mesri (Argentina) is an active member of the Academy since 2019.

LAPA organized a series of four webinars in 2020 (3 examples):

LAPA Te invitamos a formar parte de este Taller Virtual para Argentina

Importancia del Advocacy Basado en Evidencia
¿Cómo diseñar y elaborar base de datos en Salud para mejorar la incidencia?

- Importancia de los datos en salud
- Selección y Clasificación de variables
- Construcción de bases de datos y análisis de resultados

Speaker:
Dr. Martín Romero
Coordinador Ejecutivo de Salud Poblacional

Fecha: lunes 2, 9 y 16 de noviembre
Horas: 5:00 pm - 7:00 pm, (hora de Argentina)

REGISTRO
Español (Incluye máximo 2 personas por invitación)
*Incluye el acceso

LAPA Latin America Patients Academy te invita al Webinar

INTELIGENCIA EMOCIONAL
claves para enfrentar el COVID-19

con Pilar Sordo
Psicóloga con destacada experiencia en el área de la psicología clínica. Presidenta de la Fundación Cáncer Vida de Chile que ayuda a enfermos y familiares que transitan por el camino del Cáncer, ha publicado numerosos libros y estudios de investigación. Pilar es reconocida también por sus excelentes charlas motivacionales.

Lunes 18 de Mayo
11:00am hora Miami

No faltes! Reserva la fecha

LAPA

VACUNAS PARA COVID-19
ESPERANZA RETOS Y REALIDADES

Speaker:
Dr. Gilberto Castañeda

Fecha:
Viernes 18 de Diciembre 2020

09:00 AM - 10:30 PM México - El Salvador - Costa Rica - Guatemala - Nicaragua - Honduras
10:00 AM - 11:30 AM Miami - Panamá - Perú - Colombia - Ecuador
11:00 AM - 12:30 PM Venezuela - Rep. Dominicana
11:00 PM - 01:30 PM Chile - Argentina - Brasil - Uruguay

Patient Focused Medicines Development – PFMD

WAPO is a partner of PFMD since 2017 and is actively represented by Sheila Khawaja.

During 2020, Sheila has been active in two core workgroups focusing on the publication of lay-summaries and the information leaflet. The material and co-creation process involves a variety of experts from patient organizations, communications industry, publishers as well as pharma industry.

The Public Engagement Open Forum (PEOF) held a number of online live meetings where all 5 working groups had a chance to present their work and engagement the participants. Sheila moderated the session on the publication of lay summaries in June 2020.

Earlier in the year, Sheila also presented a poster on the topic at the 2020 ISMPP EU online meeting.

WAPO is now also part of the patient engagement strategic advisory board (SAB) at PFMD, represented by Sheila; the SAB met several times during the year to understand and start planning for the coming years.

Pituitary World News

The Pituitary World News representative JD Faccinetti is a WAPO Board member since 2019. In 2020 Pituitary World News continued publishing content: over 100 articles, podcasts, and educational videos were published in 2020. Additionally, PWN launched its Spanish platform, Pituitary World News en Español, in July of 2020, which will also support WAPO member organizations.

In 2020 PWN has spent several articles on WAPO and has contacted several US-based Facebook groups on Hypopituitarism, Pan-hypopituitarism, Pituitary Tumors and Cushing's to inquire about potential interest in joining WAPO. PWN expects to be hearing from someone at these groups shortly.

Due to Covid-19 restrictions, the PWN patient conference in partnership with the University of California San Francisco, Center for Pituitary Disorders, was moved from October 2020 to February 6th, 2021.

ISE – International Society of Endocrinology

WAPO has been collaborating with ISE since May 2019 on various occasions. In 2020 Pamela Funes (ISE Education Trainer) presented on: 'Patients and HCPs: An Example of Collaboration' during the WAPO eSummit.

During the year we had several contacts to discuss further collaboration, like the pre-registration discount for WAPO member organizations to ICE 2021.

Oxford PharmaGenesis

In 2020 we had little contact with Oxford PharmaGenesis. In October WAPO has contacted PharmaGenesis, and we both have decided to intensify our collaborating in 2021, on new projects.

Rare Diseases International

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases, and related to EURORDIS. Since 2018 WAPO is participating in RDI annual

meetings. We confirmed our full membership in 2019.

In 2020 RDI has started with a series of CGN4RD meetings in preparation on the WHO meetings, split in several regions: e.g. European (Sheila, Muriël), Middle East, South America (Sandra), etc.

In November 2020 WAPO was invited to a call on the **WHO Collaborative Global Network for Rare Diseases**. This call was organized to enable International Federations to share their perspective and experience on the global context for their specific rare disease area. In 2021 another meeting will be organized to discuss further where we left.

INTERNATIONAL MEETINGS

Since WAPO is increasingly recognized as a patient advocacy group, we received many invitations for online meetings in 2020. We attended several of them, to increase WAPO's visibility and to meet with new, interesting parties and potentially collaborate with. Additional can be found under each organization section..

WAPO Medical Advisory Board

Although the WAPO Medical Advisory Board (MAB) was not officially presented during the live Summit 2020, we are already collaborating with the following health care professionals. In 2021 we intend to invite more health professionals to join the MAB.

The current WAPO Medical Advisors are:

Chris Yedinak (USA)	specialist nurse
Diego Ferone (Italy)	endocrinologist
Garni Barkhoudarian (USA)	neuro-surgeon
Debora Katz (Argentina)	endocrinologist

FINANCES

The WAPO Finance Committee consists of Andrei Andrusov and Muriël Marks.

Due to a relocation, WAPO identified a new bookkeeper in Jolanda van den Berg (Zeeland, Netherlands), who took on financial reporting per January 2020.

The annual WAPO Membership Fee of €35 is meant to support the WAPO Association. The Summit registration fee of €135 is meant to support the Summit organization and expenses of the Summit (food & beverages).

WAPO choose to keep the PayPal license as a payment option to avoid high banking costs when organizations pay their Membership fee or Registration fee. Some countries do not allow PayPal and/or outgoing payments in another currency. A serious problem for organizations.

WAPO offered patient advocates - who subscribed for the WAPO Summit 2020 – to refund paid expenses (e.g. flight, registration fee, etc.) via Survey Monkey. In this way we are

willing to support patient advocates financially, to avoid any loss of expenses, after receipt of cancellation of tickets. At this moment 4 patient advocates asked for refund and many participants have chosen to transfer the prepaid registration fee to 2021.

Creative Designer

Since 2018 WAPO collaborates with the company El Cuore in Buenos Aires, Argentina. They have designed WAPO Summit banners and logos, as well as Awareness campaigns on Cushing's and Acromegaly for several years. In 2020 the designers of El Cuore created the Pituitary Month campaign, as well as the WAPO eSummit set-up (e.g. 5-anniversary logo, landing page, Thank you-page, and more) presentation slides and the eBlast designs. And lately they designed the external backgrounds in Teams and Zoom meetings.



IT

From August 2019 onwards WAPO works with the Dutch company 'Kwaaijongens', specialized in 'WordPress' websites.

Due to the Covid-19 pandemic, many other conference systems were used, like Zoom, Webex and Teams (Microsoft 365). The WAPO Board decided not to renew subscription of the GoToMeeting account. The official meeting system is now 'Teams' since it is included in the WAPO Microsoft 365 account.

WAPO CONTACT INFORMATION

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