World
Alliance of
Pituitary
Organizations

WAPO Activity Report
2022

WORLD ALLIANCE OF PITUITARY ORGANIZATIONS - WAPO 2022 ACTIVITY REPORT

INTRODUCTION

WAPO 2022 activities were in the first couple of months still influenced by Covid-19. It impacted the Global Summit, which we had to postpone from April to June 2022. And still then, most meetings were virtual, although it started to change later in 2022 to more face-to-face meetings.
The WAPO Global Summit was a great moment when we could meet each other again after 3 years, with new and old contacts within the pituitary community. Also the Ukraine pituitary patient organization was present with 2 representatives; a unique moment related to the circumstances in their country. After suggestion during the AGM discussions on June 5th – the Board accepted to set up a committee 'Transition of Care for Young Adults' to include and focus on young adults (14+ years) in 2023.
And last but not least, we have to inform you that several board members have decided to step down, due to a new position or workload in combination with their daily activities.
We will certainly miss them and thank them for all support in 2022.

The WAPO Board of Directors,
Sheila, Muriël, Sandra, Angeliki, Jorge and Clive
December 2022

WAPO Board of Directors

The Board consists of the following members, who were (re-)elected for a period of 3 years in 2022:

Mrs. Sheila Khawaja	Chair	
Mrs. Muriël Marks	Secretary / E.D.	
Mrs. Susan Kozij	Board member	
Mrs. Sandra Mesri	Board member	
Mr. Jorge Faccinetti	Board member	
Mrs. Angeliki Eleftheriou	Board member	start July 1, 2022
Mr. Clive Deverson	Board member	start September 1, 2022

WAPO Board activities

Between January 1 - December 31, 2022, the WAPO Board of Directors met via Teams in 16 Board and 2 Strategy Meetings, which on average took 1 hour.

WAPO committee structure

Since WAPO started, we have worked in several structures, since 2021 the structure is as follows:
1. Operations – incl. Daily business, Finances, Strategy, IT, Summit & AGM, and Memberships.
2. Awareness & PR – incl. Awareness campaigns, 'Transition of Care for Young Adults', Data collecting and Task Force.
3. Communications – incl. Bog, Webinar 2022 Series, campaigns.

WAPO Member Organizations
WAPO has welcomed **six** new member organizations in 2022:

- Acromegaly Canada, Canada (February 2022)
- Maternal Pituitary Support, UK (March 2022)
- Asociación Panameña de Pacientes con Acromegalia y Tumores Neuroendocrinos, Panama (March 2022)
- Leven met Acromegalie, Belgium (April 2022)
- Instituto Vidas Raras, Brazil (November 2022)
- 'Casa Hunter, Brazil (November 2022)

On December 31, 2022, WAPO represented 47 patient organizations focusing on Pituitary, Adrenal and Rare diseases.

WAPO Medical Advisory Board

Per 31 December 2022 the Medical Advisory Board is represented by the following health care professionals:

Christine Yedinak (USA)	specialist nurse
Diego Ferone (Italy)	endocrinologist
Federico Gatto (Italy)	endocrinologist
Garni Barkhoudarian (USA)	neuro-surgeon
Debóra Katz (Argentina)	endocrinologist
Elena Valassi (Spain)	endocrinologist – research

In 2023, WAPO will look for more medical advisors, with a special focus on disease-related experts.

OPERATIONS

Finances
The WAPO Finance Committee consists of Muriël Marks, Clive Deverson and support of Angeliki Eleftheriou. An external, independent bookkeeper JB Advies (Netherlands) is available for questions and prepared the quarterly financial overviews and the Annual Finance Overview.

During the AGM of June 5, 2022 the WAPO Board of Directors were granted **'APPROVAL'** for 'All WAPO 2021 Activities as well as 2021 Finances'.

In 2022, the annual WAPO Membership Fee of €35 was invoiced again. However, several patient organizations were not able to pay for the fee and banking costs, which WAPO waivered for them.

Several project (extern) activities generated income in 2022, which WAPO used to support patient advocacies who were in need of finances to organize an awareness campaign, and WAPO paid 5 times membership fees of patient organizations who couldn't afford in 2022.

IT
From August 2019 onwards WAPO works with the Dutch IT services company 'Kwaaijongens', specialized in 'WordPress' websites and M365 support via a partner company 'Linternet'.

Mid 2022 the WAPO Board decided to improve the quality of the website, and build a new website in WordPress, incl. a Webinar/Information Library and a 'Health & Exercises Information' page. Due to workload, the release is now scheduled for January 2023.
All content will be available in open access. Patient organizations, medical advisors and third parties are invited to share information, brochures/leaflets, also in other languages, which WAPO will add in the disease section, so people living with the condition will be able to upload the information.

Creative Designs
Since 2018 WAPO collaborates with the company El Cuore in Argentina.
In 2022, El Cuore has supported WAPO with designs for the WAPO 2022 Webinar Series, the WAPO Summit, logo for the Global Café sessions and Awareness Campaigns.

WAPO ACTIVITIES IN 2022

SUMMIT
In 2022 it was finally possible to organize a live WAPO Summit, the first one since 2019, where patient advocates could meet and discuss in person again!
Although we had to postpone the Summit of April 1-3, 2022 to June 3-5, supported by the flexibility of the hotel and Lumanity and interpreters, the number of registrations was still high. All speakers reconfirmed their interest to be present at this new date. Due to travel- and covid restrictions as well as lock down, a large number of patient advocates were not able to participate. With a lower number of patient advocates incl. many new faces, we held a great and informative Summit 2022.
The WAPO Board made it possible for the Ukraine delegation to participate 'live' during the Summit program.
During the Summit the 'WAPO International Recipe Book' was launched and handed out to all participants and speakers.
Presentation recordings will be shared on the Library of the new WAPO website.
The Summit was made possible with support of Ipsen, Novartis, Recordati Rare Diseases, Pfizer, HRA Pharma Rare Diseases, Camurus and Crinetics.

Summit presentations:

Friday, June 3
'**Best Practices'** by Patient Advocates from Belgium, Canada, Lithuania, Ukraine and Netherlands;
"Bone Density' by *Natasha Appelman-Dijkstra* (endocrinologist specialized in osteoporosis, metabolic bone diseases and calcium/phosphate disturbances, LUMC, Netherlands);
'European Society of Endocrinology – shaping the future of endocrinology – a joint effort' by *Dirk De Rijdt* (ESE Director of Strategic Partnerships**,** Belgium)**.**

Saturday, June 4
'Importance and Outcomes of WAPO Mapping Project 2021' by *Sandra Mesri* (APEHI, WAPO, Buenos Aires, Argentina)
'**Newest Insights Research Acromegaly and Cushings'** by *Elena Valassi* (Associate Professor of

Endocrinology, Hospital Universitari General de Catalunya and Hospital Sant Pau, Spain);
'Acromegaly Perspectives' by *Pamela Funes* (International Society of Endocrinology, Netherlands) with *Chris Yedinak and Sheila Khawaja;*
'Fatigue Management' by *Samantha Harbut* (Specialized in Pain and Fatigue Mngt., NHS Dorset Healthcare Trust, England);
'Patient/Person centered care in pituitary disorders' by *Nienke Biermasz* (internist-endocrinologist, Leiden UMC, the Netherlands – on behalf of the International Society of Endocrinology);
'Discussion on new video's' by *Chris Yedinak* (OHSU, FINE, WAPO Medical Advisor, USA)
'Brain Fog and other cognitive challenges in pituitary tumors' by *Garni Barkhoudarian* (Pacific Neuroscience Institute, California, WAPO Medical Advisor, USA) – virtual.

Sunday, June 5
'WAPO Annual General Meeting (only for WAPO Member Representatives Medical Advisory Board)
Discuss 2022/2025 Activities (WAPO Member Organizations / Medical Advisory Board)

Comments after the Summit:

Delegate: *WAPO Conference was amazing 😀 I truly enjoyed attending.*

Speaker: *It has been a real pleasure attending the summit and, as usual, I learnt a lot from the patients! Interest, enthusiasm and level of involvement of the community have clearly risen a lot and advisors suggested many interesting points which will certainly help WAPO grow and improve even further. You must be very proud, since this is the result of your inspirational ideas, hard work and perseverance!*

Delegate: *It was a lovely WAPO Global Summit, I enjoyed it a lot, thanks for the splendid organization.*

Speaker: *I would like to thank you and congratulate you for an excellent WAPO summit! It was so important for me to be there; I learned a lot from everyone.*

Interpreter: *It was great to see you and the rest of the WAPO family again, especially after such a long time. Seeing the energy and drive you put in WAPO's projects is very inspiring. The talks were very interesting!*

Delegate: *Thank you for the most wonderful and positive summit. I came back with so much new knowledge and so many new ideas, which I already shared with my little group of co-patients, nurses and doctors here.*
The meeting was really well planned, on a high level professionally with inspiring personal contributions. We laughed a lot, but tears were also not far away! The atmosphere was extremely trusting, it was my feeling that everybody got to say what they needed to say, and we all listened attentively to the presentation of the carefully prepared papers and each other.
The talks included all pituitary diseases and Addison's - and yet I felt they were all directed to me who have knowledge and experience only of Acromegaly.

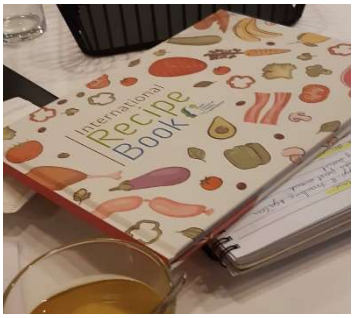
Delegate: *Thank you so much for the invitation. It was really a great experience for me.*

Annual General Meeting

On June 5, the AGM was held live again with 13 patient advocacies in person and 'proxy voting' by 10 patient advocacies, which made we had quorum for voting.

We had a short AGM, incl. approval for all 2021 activities and finances. Afterwards we had a discussion round, where we learned many interesting ideas, which WAPO will follow-up on.

The minutes and actions were shared with the WAPO member organizations.



WAPO Blog 'Global Pituitary Voice'

In 2022 WAPO sent out several blogs in various topics. However, due to lack of manpower, we couldn't follow-up further in 2022. We hope to restart in 2023, possibly with 2 medical writers to support us.

WAPO 2022 Webinar series

WAPO organized seven educational webinars in 2022, on important and interesting new topics e.g. 'Plain Language Summaries' as well as informative updates and research outcomes.
The below topics were presented and recorded for the new website library, in English and Spanish.

February 18	**How can we detect acromegaly earlier?**	**Michael Cusimano, Canada**
Mar-17	***Plain Language Summaries***	**Elena Conroy, UK**
Apr-27	***Can new technologies and artificial intelligence benefit long-term outcome in pituitary diseases? Towards a future personalized treatment***	**Susan Webb, Spain**
May 18	***Osteoporosis in Pituitary Patients***	**Elena Valassi, Spain**
Oct-07	***Protocol for Acromegaly Patient Care***	**Deanna Badiuk, Acromegaly Canada**
Oct-27	***Fighting Against the Global Issue of Substandard and Falsified (SF) Medicines: A stakeholder engagement approach***	**Bahijja Raimi-Abraham; Fight the Fakes Alliance UK**
Nov-17	***Labor and a chronic illness, e.g. adrenal cortex insufficiency and Cushing'***	**Johan Beun, AdrenalNET**

With great thanks for support of the following companies, who made the 2022 Webinar Series possible: Ipsen, Recordati Rare Diseases, HRA Pharma Rare Diseases, Camurus, Crinetics.

WAPO Awareness Activities

'Awareness' was one of the key priorities of WAPO activities in 2022.

Rare Disease Day – February 28 2022

On Rare Disease Day 2021, the International Society of Endocrinology worked together with WAPO and Dr. Susan Webb in a panel session. Sheila Khawaja joined in the role of Patient Expert.

On several occasions, WAPO collaborated with external pharmaceutical companies in finding a 'Patient Expert' or 'Medical' speaker for internal and/or external webinars and interviews. WAPO board members are also invited to participate in research or long-term projects. Some of these research outcomes have been published in 2022.

- Acromegaly: internal online meeting where Sheila Khawaja and Angeliki Eleftheriou shared information on WAPO and their experiences with Acromegaly;
- Acromegaly, external webinar where Marie Louise Sodemann (Patient Expert, Denmark) shared her experiences with Acromegaly in a panel discussion with Susan Webb, and others.
- Interview Acromegaly Day – company interview on Acromegaly with JD Faccinetti.
- Support in finding Patient Experts on disease level for medical teams.
- Annual Members meeting of Acromegaly Canada (September 16-18 – Vancouver, Canada) WAPO attended the annual meeting for the first time, to better understand the needs of a national organization in a completely different region compared to the EU.

Publications – Poster presentations:

1. https://www.endocrine-abstracts.org/ea/0081/ea0081p432

Endocrine Abstracts (2022) **81** P432 | DOI: 10.1530/endoabs.81.P432

ECE2022 > Poster Presentations > **Pituitary and Neuroendocrinology** (127 abstracts)

A systematic literature review to evaluate extended dosing intervals in the pharmacological management of acromegaly

Maria Fleseriu [1], Zhaoyun Zhang [2], Kate Hanman [3], Keval Haria [3], Aude Houchard [4], Sheila Khawaja [5], Antonio Ribeiro-Oliveira [6] & Monica Gadelha [7]

2. https://link.springer.com/article/10.1007/s12325-022-02360-6 (article)

Original Research | Published: 11 December 2022

PRESTO 2: An International Survey to Evaluate Patients' Injection Experiences with the Latest Devices/Formulations of Long-Acting Somatostatin Analog Therapies for Neuroendocrine Tumors or Acromegaly

Dermot O'Toole, Pamela L. Kunz, Susan M. Webb, Grace Goldstein, Sheila Khawaja, Mark McDonnell, Sandra Boiziau, Delphine Gueguen, Aude Houchard, Antonio Ribeiro-Oliveira Jr & Ally Prebtani

Advances in Therapy (2022) | Cite this article

571 Accesses | **1** Altmetric | Metrics

3. https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-022-00334-0
   https://pubmed.ncbi.nlm.nih.gov/35109927/
   Publication of outcomes of study, published in magazine 'Research Involvement and Engagement', February 2, 2022. With special thanks to Sandra Mesri (APEHI) and Deanna Badiuk (Acromegaly Canada) for their participation in the interview series of selected patient organizations, which confirmed insights and gave us additional information.

Gorbenko *et al.*
Research Involvement and Engagement (2022) 8:1
https://doi.org/10.1186/s40900-022-00334-0

Research Involvement and Engagement

RESEARCH ARTICLE Open Access

Co-creating with patients an impact framework across the medicine's life cycle: a qualitative study exploring patients' experiences of involvement in and perceptions of impact measures

Oleks Gorbenko[1], Pascale Cavillon[2], Rachel H. Giles[3], Teodora Kolarova[4], Muriël Marks[5], Antonella Cardone[6], Sandeep Bagga[7*] and Claire Nolan[7]

Some external activities generate income, which we used to support patient advocacies who were in need of income, and for some patient organizations WAPO paid their membership fee for 2022. Renumeration of patients and patients advocates for their time and knowhow is discussed several times by WAPO.

Cushings' Awareness campaign - April 8 2022
WAPO did not create a new 2022 Cushing's Awareness campaign. WAPO was invited to work together in a campaign of HRA Pharma Rare Diseases.

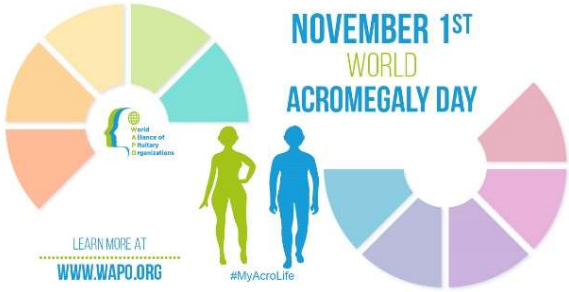
Hormones Day – May 23 2022
During ECE 2022, a new international awareness day was launched: 'Hormones Day'.
WAPO is very interested to share and promote this day in the upcoming years!
Recently a new day was selected by ESE for Hormones Day: May 15th.

Pituitary Month – October 2022
WAPO contributed to Pituitary Month with three activities and support to 2 patient organizations:
1. webinar: 'Value of Treatment Guides' by Deanna Badiuk, Patient Expert Acromegaly Canada, Canada
2. webinar: 'Fighting Against the Global Issue of Substandard and Falsified (SF) Medicines: A stakeholder engagement approach' by Dr. Bahijja Raimi Abraham, Fight the Fakes Alliance UK, King's College UK

3. campaign with awareness poster

<u>Acromegaly Awareness campaign – November 1 2022</u>

The 2022 Awareness Campaign included informative posters, which were shared in many countries. At least 11 Patient Organizations and companies reshared the campaign with their logo and/or translated versions e.g. Acromegaly Community Inc., CSRF, ABAB Bulgaria, Pituitary Alliance Greece, Rare Diseases International, COR2ED, International Society of Endocrinology, IPSEN, Camurus, and more.



DATA & MAPPING

In 2022 the WAPO Board decided to organize another Mapping project in 2023/2024 (Q4/Q1). During the Summit 2022, Sandra Mesri presented on the Mapping Project and emphasized on the importance to learn about the issues patient communities meet. With this knowledge, WAPO can support all organizations in a better way.

EXTERNAL PROJECTS

WAPO participated in 2022 in several external projects, organized by other stakeholders. Due to confidentiality regulations, we cannot share the projects here.

WAPO PARTNERS AND MEMBERSHIPS

WAPO is always looking for value creating partnerships with which parties we can support patient organizations and their members. In 2022 the number of external activities was lower than 2021. Many conferences were still online.

ADRENALNET – ADRENALS.EU

AdrenalNET is an online community for adrenal diseases, based in the Netherlands, mainly focusing and collaborating with European patient organizations. WAPO follows activities of AdrenalNET and AdrenalNET's coordinator Johan Beun presented in a webinar on November 17th regarding a labor project in the Netherlands.

European Society of Endocrinology (ESE) / European Congress of Endocrinology (ECE)
Since January 2022, WAPO has an 'Affiliate Patient Organization' Membership of ESE, for which we are very proud.
In May, ECE 2022 was organized in Milano, Italy. Due to illness of Muriël Marks, Sheila Khawaja participated alone. Sheila met interesting parties to collaborate with in near future. ECE 2022 provided patient advocates with a proper stand in the 'Patient Zone'. During ECE 2022 also Hormone Day was launched.
During a separate meeting for patient advocates, a new ESE Patient Advisory Board was announced, for which organizations could candidate. WAPO was one of the candidates, but was not elected.
During Pituitary Month 2022, the WAPO Awareness poster was shared by ESE.

EURORDIS
Eurordis strengthens the patient voice and shapes research, policies and patient services.
Interesting news or webinars are shared with WAPO members through WAPO social media, e.g. the training courses. Eurordis also shared several WAPO webinar announcements in 2022.

European Patients' Forum
The European Patient's Forum (EPF) is an umbrella patient advocacy in Europe, an intermediator between the patient community and EU policymakers, by providing a cross-disease perspective based on issues regarding chronic conditions.
Since 2022 WAPO is a Full Member, we receive interesting news and invitations for webinars and online meetings. EPF also reshared WAPO webinar announcements.
'Data Saves Lives' Bootcamp (October 10-11, Prague, Czech Republic): A 2-day brainstorming event on the concepts of the use of patient's data, how to protect it and how to make the best use of it. The selection committee selected 12 patient group representatives, and Sheila Khawaja was among the selected.

FindMeCure
FindMeCure is an organization which links the clinical research industry and people looking for a new, alternative treatment via Clinical Trials. WAPO and FindMeCure are partners since 2017.
On January 16, WAPO spoke with FindmeCure on the topic 'What is the role and the challenges of a patient advocate?'. The outcomes did support FindMeCure better in their focus on a more holistic approach to rare, chronic diseases in their 'Medication Hub', which was by then only accessible for industry. The project is finished and visible on their website.

Federation of International Nurses in Endocrinology (F.I.N.E)
WAPO is a member of F.I.N.E. since 2018 and collaborating with Christine Yedinak in several projects, e.g. 'adrenal insufficiency in covid era' as well as the following:
On behalf of F.I.N.E., Chris Yedinak found funding and a company to make a series of animated videos with pituitary disease related information, as well as accompanying medical texts for the new WAPO website. This work is highly appreciated by WAPO, and we especially wish to thank Chris Yedinak for all effort and time she put in the series! The animated video's were also discussed during the Summit, and the audience was very enthusiast.
F.I.N.E. also reshared the 2022 webinar announcements.

GAFPA (**G**lobal **a**ccess **f**or **P**atient **A**dvocacy)
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.

International Alliance of Patient Organizations
Since 2021, WAPO is officially accepted as a full member of IAPO, which we think is an organization which completes the WAPO activities.

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

Patient Focused Medicines Development – PFMD
WAPO is a partner of PFMD since 2017 and is actively represented by Sheila Khawaja in various workgroups, e.g. Patient engagement strategic advisory board (SAB).

Pituitary World News
The Pituitary World News representative JD Faccinetti is a WAPO Board member since 2019.

International Society of Endocrinology (ISE)
Since 2019 WAPO is collaborating with ISE on several occasions, e.g. webinars.
For Rare Disease Day, ISE organized a webinar titled 'Pituitary disorders through the eyes of three different experts in various phases or aspects' in which Sheila Khawaja participated in a panel discussion with Dr. Susan Webb and Ass.Prof. Christine Yedinak. ISE was also present at the WAPO Summit 2022, and invited a speaker on their behalf, Nienke Biermasz (LUMC, Netherlands).

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 2019 WAPO has a full membership. In 2022 we participated in several webinars and RDI reshared the WAPO Pituitary Month campaigns.

World Patients Alliance
WAPO became a member in 2021 of WPA, a non-profit organization which is supporting patient organizations and patients, with a focus on all disorders.

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