



World Alliance of
Pituitary Organizations

WAPO Activity Report 2023

WORLD ALLIANCE OF PITUITARY ORGANIZATIONS - WAPO 2023 ACTIVITY REPORT

INTRODUCTION

Dear Reader,

2023 started positively with 3 Board members and great plans scheduled for 2023!

We were very glad when we found 2 more people to join the WAPO Board - within the first 2 months - and from there we became more and more active.

The launch of the new website in January and the start of the 2023 Webinar Series brought back the spirit again. Also the focus on the WAPO Global Summit, in October, in Argentina gave a lot of energy. Our collaboration with the designers of El Cuore resulted in a new logo and some excellent banners and a flag for use at the summit and conferences.

Our collaboration with Caretently started a promising range of Blogs, which will continue in 2024.

WAPO express our special thanks to pharmaceutical companies. With their support it has been possible to execute the 2023 WAPO plans. (Note: Although WAPO is an official charity, we do not receive government funding).

We look forward to continuing collaboration with all WAPO Member organizations and other stakeholders in 2024!

The WAPO Board of Directors,
Sandra, Clive, Robert & Muriël
December 2023

WAPO Board of Directors

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

Mrs. Muriël Marks	Board member
Mrs. Sandra Mesri	Board member
Dr. Clive Deverson	Board member
Mr. Robert Brady	Board member
Mrs. Leslie Edwin	Board member*

* Mrs. Edwin was a WAPO board member between February - November 2023.

WAPO Board activities

Between January 1 - December 31, 2023, the WAPO Board of Directors had 14 meetings via Teams and meetings in person, before and after the Summit 2023.

WAPO committee structure

Since 2021 WAPO works within the following committee streams:

- 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 Member Support.
- 3. Communications** – incl. ‘Blogs & Vlogs’.

WAPO Member Organizations

WAPO has officially welcomed the following 5 member organizations in 2023:

- **Child Growth Foundation**, UK (February 2023)
- **Raymond A. Wood Foundation**, US (May 2023)
- **Got Arginine Vasopressin Deficiency? | Got Diabetes Insipidus?**, US (June 2023)
- **Acromegaly Philippines**, Philippines (September 2023)
- **APEPOF**, Argentina (September 2023)

On December 31, 2023, WAPO is representing 52 patient organizations, who are focusing on various disorders, e.g. pituitary, adrenal and related rare diseases.

WAPO Medical Advisory Board

Per 31 December 2023 the Medical Advisory Board is represented by the following healthcare professionals:

Christine Yedinak (USA)	Endocrinology Nurse
Diego Ferone (Italy)	Endocrinologist
Federico Gatto (Italy)	Endocrinologist
Garni Barkhoudarian (USA)	Neuro-surgeon
Debóra Katz (Argentina)	Endocrinologist
Elena Valassi (Spain)	endocrinologist – research

In 2024, WAPO will contact medical advisors for extending their position as well as find other disease related experts to join the Medical Advisory Board.

OPERATIONS

Finances

The WAPO Finance Committee consists of Muriël Marks and Clive Deverson.

Independent bookkeeper JB Advies (Netherlands) is reviewing the finances and prepares the quarterly and annual financial overviews since 2020.

During the online Annual General Meeting of May 25th, 2023 the WAPO Board of Directors were granted '**APPROVAL**' for 'All WAPO 2022 Activities as well as 2022 Finances'.

During the live AGM on October 8th (Argentina) there were no further questions on the 2022 activities and 2022 finances by patient advocates who didn't participate in the online AGM.

In 2023, member organizations received the invoice for their annual membership through PayPal. WAPO waived 2 patient organizations to pay for their membership in 2023.

IT

Since 2019, WAPO collaborates with the Dutch IT services company 'Kwaaijongens', specialized in 'WordPress' websites and M365 support.

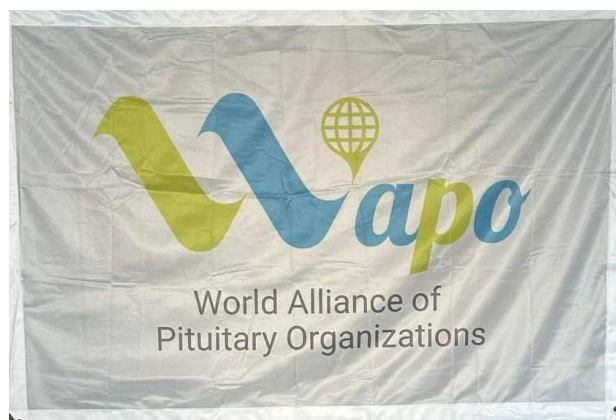
This company also supported WAPO with the new format of the website, which was released on January 27th, 2023.

The new WAPO logo was integrated in the website design from May 2023 onwards.

Creative Designs

Since 2018 WAPO has collaborated with the company El Cuore in Argentina.

In 2023, El Cuore was responsible for the WAPO Global Summit and 2023 Webinar designs. A special project was the WAPO flag design. WAPO used it for the first time at the WAPO Global Summit 2023.



WAPO ACTIVITIES IN 2023

WAPO Global Summit 2023

In 2023 the WAPO Global Summit was held in Buenos Aires, Argentina, on October 6-7-8. The Novotel Buenos Aires was a good venue for the Summit. Patient Advocates and Nurses from all over the world participated and registered via the event registration platform.

All sessions were hosted by Clive Deverson (WAPO Board) and each topic was followed with Q&A or discussion.

All sessions were available to follow in English and Spanish, with 2 interpreters on location, and were recorded in both languages for sharing on the WAPO website, see: <https://www.wapo.org/library/>

The Summit was made possible with support of IPSEN, Recordati Rare Diseases, HRA Pharma Rare Diseases (Perrigo), Novo Nordisk, Crinetics and Ascendis Pharma.

We thank all pharmaceutical companies for their trust and support to WAPO!

Please find the Global Summit presentation topics below:

Friday, October 6:

1. **'Best Practices'** by *Patient Advocates & Nurse;*
2. **'Clinical trials'** by *Sabrina Brignardello* (Un Ensayo para Mí, Argentina)
3. **'Redescubriendo Mi ONG'** by *Manuela Pelleri* (Advocacy Group, Argentina)

Saturday, October 7:

1. **'How will patients find the right place for treatment'** by *Alvaro Campero* (neuro-surgeon, Hospital Angel C. Padilla, Tucumán, Argentina)
2. **'Growth Hormone Deficiency in Adults & Children'** by *Chris Yedinak* (Associate Professor, Oregon Health & Sciences University Portland. OR. USA)
3. **'Evolution of pituitary surgery and current state of the art in the surgical treatment of pituitary tumors'** by *Alvaro Campero* (neuro-surgeon, Hospital Angel C. Padilla, Tucumán, Argentina)
4. **'Belgian approach of the home care educational program for patients with acromegaly: crucial role of the endocrine nurse for improved patient satisfaction'** by *Els Rutten* (Endocrine Nurse & 'Living with Acromegaly', Hospital Gent, Belgium)
5. **Short presentations:** Interaction Pharmaceutical companies, Global Cushing Survey, Patient Support, Training social media.

Sunday, October 8

1. Annual General Meeting for the Patient Advocates; and
2. Medical training for the Nurses, focusing on pituitary disorder related topics, by Ass.Prof. Chris Yedinak (OHSU, USA).



Host Clive Deverson



Speaker Sabrina Brignardello



*Question by Jianmin Chen
(Hypercortisolism PAG, China)*



Four Nurses with their certificates, trainer Chris Yedinak and Sandra Mesri & Muriël Marks (Board)



WAPO Blog 'Global Pituitary Voice'

In 2023 WAPO sent out a number of blogs via Mailchimp and the WAPO website, covering topics like 'Cortisol Pump', 'HTA', 'Webinars to watch', 'Why patient organizations are vital to both patients and healthcare professionals', etc.

WAPO collaborated with the professional blog writer Natasha Barr of Caretently.

The blogs are available on the WAPO website via: <https://www.wapo.org/blogs/>

WAPO 2023 Webinar series

WAPO organized 8 educational webinars in 2023, which were hosted by Clive Deverson (WAPO Board) and with technical support by the Production Man (England), and interpretation by Patricia Vega into Spanish.

All webinar recordings were shared on the WAPO website, in open access and in both English and Spanish, via: https://www.wapo.org/library/?_library_category=webinar

With great thanks to our sponsors, who made the '2023 Webinar Series' project possible:

IPSEN, Recordati Rare Diseases and Camurus.

Please find below the topics and speakers:

Release Date 2023:	TOPIC Webinar:	Speaker:	Status
January 27	Mental Health Support after diagnosis	Ignas Meskauskas	<i>released</i>
February 28	Pain in Pituitary Disorders	Emilio Covarrubias	<i>released</i>
March 30	Hypercortisolism - History	Lewis L Blevins	<i>released</i>
April 27	Depression and the Pituitary Patient	Linda M Rio	<i>released</i>
May 25	Health Technology Assessment	Realise Advocates	<i>released</i>
September 28	Clinical Trials	Alberto Pedroncelli	<i>released</i>
October 26	Transition - from child to adult treatment	Kirsten Davidse	<i>released</i>
November 30	Growth Hormone Deficiency in Adult & Children	Chris Yedinak	<i>released</i>

WAPO Awareness Activities

‘Awareness’ is always important when raising more attention for rare disorders.

In 2023 our focus was on the below disorders and awareness days.

Rare Disease Day – February 28 2023

Again, WAPO participated in the Rare Disease Day campaigns, while promoting and resharing campaigns and informing the patient organizations of the campaign kits (e.g. banners, posters, etc.) which were provided. Also WAPO Board member Robert Brady shared his story during the Rare Disease Day, as a part of the campaign.

Cushings’ Awareness campaign - April 8 2023

WAPO created another Awareness campaign with two posters (Date and Symptoms) and reshared this with the WAPO Member organizations as well as with third parties. The campaign was well (re)shared on social media.

- a ‘social media take-over’ of the ‘Rare Revolution Magazine’ was organized by Robert Brady.
- support to an external campaign by HRA Rare Diseases/Perrigo; where 5 podcasts were pre-discussed with the organizer.
- support to an external campaign by Recordati; where a new Cushing website was launched and resharing on social media.

European Hormone Day – May 15 2023

WAPO participated with the ESE toolkit for ‘European Hormone Day’ and reshared all information, which got many likes and reshares. WAPO was also present at ECE2023 to celebrate **EHD** on May 15.

Addison’s Day | Adrenal Insufficiency – May 29 2023

WAPO created attention for this day with an Awareness Poster (Date and Symptoms).

We sought for collaboration, and will also do so next year.

Pituitary Month – October 2023

In 2023, WAPO organized 3 activities in October ‘Pituitary Month’:

- the WAPO Global Summit 2023, on October 6-7-8, 2023
- a webinar, where Kirsten Davidse, Erasmus MC Rotterdam, the Netherlands presented how they support young adults in their transition to adult treatment.

See: <https://www.wapo.org/library/webinar-7-2023-transition-of-paediatric-care-to-adult-care/>
- a blog on the 'WAPO Webinar Series 2023' to give more attention to important disease related topics. Read: <https://www.wapo.org/8-webinars-to-watch-this-pituitary-awareness-month/>

Acromegaly Awareness campaign – November 1 2023

Due to many activities related to the Summit, WAPO repeated the 2022 awareness campaign with the new logo. The 2023 campaign was reshared many times and received many likes.

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.

EXTERNAL PROJECTS

In 2023 WAPO participated in several external projects, organized by other stakeholders.

We cannot share all details of the projects, therefore we will share these in general terms:

- review 2 brochures e.g. on Acromegaly and Cushing's (Deanna Badiuk (Acromegaly Canada), Marie-Louise Sodemann, Hypofysenetverkaet, Denmark, Muriël Marks (WAPO));
- support to find patients / patient advocates to support companies in understanding the burden of the disease and journey of a patient and/or patient advocate;
- various roles in medical studies (active participation, review, interview and/or supporting role), e.g.:

1. *'Health state utility value of Cushing syndrome patients after bilateral adrenalectomy – systematic literature review and mapping to EQ-5D'*

A 'review on research outcomes by an external company' and held interviews with patient advocates/patients, initiated by Recordati Rare Diseases. A review team of HCPs and WAPO's M. Marks checked for the outcomes and content. The outcomes were presented in an ePoster at ECE2023.

2. *'Key Device Attributes for Injectable Somatostatin Receptor Ligand Therapy in Acromegaly and Neuroendocrine Tumours'* – study by COR2ED, healthcare professionals, INCA and WAPO; financially supported by IPSEN.

Outcomes were presented in a poster at ENDO 2023.

DATA & MAPPING

Due to changes in the Board and Finances, WAPO has rescheduled the Mapping Project III to 2024.

WAPO PARTNERS AND MEMBERSHIPS

WAPO is always looking for valuable partnerships with which all parties we can support patient organizations and their members.

ADRENALNET – ADRENALS.EU

AdrenalNET is an online community for adrenal diseases, based in the Netherlands, focusing and collaborating with European patient organizations. AdrenalNET provided disease information in printed version for the delegates and Nurses at the WAPO Global Summit 2023.

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

Since January 2022, WAPO has an 'Affiliate Patient Organization' Membership of ESE, which we very much appreciate.

In 2023, WAPO participated with 2 persons in the ECE 2023 in Istanbul, Türkiye; and joined in the ESE Patient Advocacy Board meeting. WAPO received support in the travel expenses.



EURORDIS

Eurordis strengthens the patient voice and shapes research, policies and patient services.

In 2023, interesting news, training or other were shared via the WAPO social media with the WAPO member organizations.

European Patients' Forum

The European Patients' Forum (EPF) is an umbrella patient advocacy group in Europe, being an intermediary between the patient community and EU policymakers by providing a cross-disease perspective based on issues regarding chronic conditions. Since 2022 WAPO has been a Full Member.

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 have been partners since 2017. On January 16, 2023, 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 has been a member of F.I.N.E. since 2018 and collaborating with Christine Yedinak in several projects, in 2023.

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 (launch January 27th, 2023). 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!

F.I.N.E. also made it possible for one nurse to participate in the 2023 Global Summit in Argentina. Chris Yedinak also presented in the WAPo 2023 Webinar Series regarding '*Growth Hormone Deficiency in Children and Adults*'. (see <https://www.wapo.org/library/>)

GAFPA (Global access for Patient Advocacy)

Sandra Mesri (Argentina) has been 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 (IAPO)

Since 2021, WAPo has been officially accepted as a full member of IAPO, which we think is an organization which compliments the WAPo activities.

Latin Patient Academy (LAPA)

Board member Sandra Mesri (Argentina) has been an active member of the Academy since 2019.

Patient Focused Medicines Development – PFMD

WAPo has been a partner of PFMD since 2017.

Pituitary World News

The Pituitary World News is an active news gathering company, with interesting podcasts as well related to pituitary topics. Each month, WAPo is in contact with co-founder JD Faccinetti, to discuss activities new ideas and possibilities for collaboration.

Co-founder Lewis S. Blevins Jr. joined the 2023 Webinar Series 2023 with a presentation on '*Cushing's Syndrome; a cursory look into the past*'.

International Society of Endocrinology (ISE)

In 2023 WAPo reshared several webinars which ISE was organizing.

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 had full membership.

World Patients Alliance

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

WAPO Contact Information

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