



World Alliance of
Pituitary Organizations

Activity Report 2025

an overview of 2025 WAPPO activities

2025 marks an incredible milestone for us as we celebrate 11 unofficial years of dedication and service, led by our passionate board members and volunteers! As we wrap up this year, we are thrilled to share that we stand strong with 6 outstanding Board members, each bringing unique skills and insights to guide WAPO into the exciting journey of 2026! And what a year it will be as we officially celebrate WAPO's 10th anniversary!

This review of 2025 is bittersweet, as it serves as our final look back using the 'World Alliance of Pituitary Organizations' name. Starting January 1st, we will proudly embrace our new name, Worldwide Adrenal and Pituitary Organizations, 'WAPO', which you can read more about in this document.

This past year has been bustling with activity, capped by our engaging Blogs & Vlogs Series and the flagship event WAPO Global Summit! We also made waves with our Cushing's Disease Awareness video and supporting awareness campaigns.

A huge shoutout to our invaluable medical advisors! Your support and guidance have been instrumental in answering our questions and shaping our initiatives.

We are also deeply grateful to the pharmaceutical companies for their generous in-kind and financial support, and for the exciting opportunities to collaborate on their projects.

Looking ahead, we can't wait to continue our journey and work hand-in-hand with all our amazing stakeholders in 2026—patient organizations, healthcare professionals, pharmaceutical companies, supportive businesses, and beyond! Here's to a fantastic year ahead!

**The WAPO Board of Directors,
Sandra, Robert, Aparna, Chris, Roz & Muriël**

December 2025

WAPO Board of Directors

The WAPO Board was re-elected during the Annual General Meeting on October 12, 2025, for 3 years. Board members are:

Muriël Marks Board member

Sandra Mesri Board member

Robert Brady Board member

In February 2025, Clive Deverson choose to withdraw from the Board, due to personal reasons.

New Board members:

The following nominees were elected at the WAPO AGM on October 12, 2025:

Christine Yedinak DNP,FNP,MN, Grad Dip ED; Retired Nurse Practitioner; Adjunct Professor:
Mount Marty University, USA

Aparna Sahana Patient Advocate Acromegaly Community India

Rosalind Way Patient Ambassador Pituitary Foundation UK

Nominees will first collaborate with the current board members for a term of 6 months.

During the next online AGM, nominees will become official board members.

WAPO Board Meetings

Given the varying locations, WAPO Board members held **18** online board meetings in 2025.

In the days leading up to the Summit, and after the Summit and AGM, we held in-person meetings to explore a wider range of topics.

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, Data collecting and Member Support.
- 3. Communications** – incl. ‘Blogs & Vlogs’.

WAPO Member Organizations

WAPO has officially welcomed 1 new member organization in 2025:

- **Addison’s Disease Self Help Group**, UK

WAPO Affiliate Member in 2025

In 2025, WAPO started with a new kind of membership for companies and interested health care professionals, the **Affiliate Membership**. The first company to accept this, was:

- **Pituitary World News**

In 2026, WAPO will start a campaign to promote and offer an affiliate membership to companies and organizations as well as to healthcare professionals, nurses and other stakeholders at an annual sum, incl. an invitation to the Summit and involvement in projects and campaigns.

Per December 31, 2025, WAPO is representing **42** patient organizations, in **30** countries, focusing on pituitary and adrenal disorders, e.g. acromegaly, Cushing’s Disease, adrenal insufficiency, AVP-d, and related disorders.

WAPO Medical Advisory Board

Per January 2025, the Medical Advisory Board is represented by the following healthcare professionals:

Chris Yedinak	Adjunct Professor: Mount Marty University USA
Federico Gatto	Assistant Professor in Endocrinology at University of Genova, Italy
Debóra Katz	Director Neuroendocrinology at FLENI Hospital Buenos Aires, Argentina
Elena Valassi	Associate Professor Endocrinology, International University Catalonia, Spain
Noa Tal	Endocrinology, Providence Hospital, USA
Cihan Atila	Neuro-Endocrinology-Research, University of Basel, Switzerland

Garni Barkhoudarian, Neurosurgeon at Pacific Neuroscience Institute, USA, decided in January to step down, after 6 years, and introduced Dr Noa Tal to take his place. We thank Garni for his support.

We are very thankful for the supportive role of all medical advisors. e.g. support with external requests, reviews, participation in projects, and more in 2025.

OPERATIONS

Finances

In 2025, the WAPO bookkeeping was executed internally and supported by an external company, with which WAPO collaborates since 2020.

The Annual membership fee was invoiced through PayPal. Due to higher PayPal costs, WAPO is looking for other options to receive and make payments.

Annual General Meeting

Online AGM – June 12, 2025

During the online WAPO AGM on June 12, 2025, the WAPO Board of Directors were granted **‘Approval’** for all WAPO 2024 Activities and Finances.

And **‘Approval’** was received for adaption of the Bylaws, section ‘Affiliate membership’ text.

Live AGM – October 12, 2025

During the live WAPO AGM on October 12, 2025, the following topic were discussed and approved:

1. Change of name:

Since the 2024 October AGM, ways to give more visibility and invitation to adrenal insufficiency patient organizations were reviewed, which resulted in a new name per January 1st, 2026:

Present patient advocates at the October 2025 AGM, choose the following new name:

‘Worldwide Adrenal and Pituitary Organizations’

2. Nominations & Re-Elections, as described earlier in ‘Board members’

The current board members Robert Brady, Sandra Mesri and Muriël Marks were re-elected for a 3 year term (2025- October 2028).

Nominees Chris Yedinak, Aparna Sahana and Roz Way, were elected as nominees for a 6 month term, and will become official board members during the online AGM in April 2026.

The 6-months term will be held for all new board members from 2025 onwards, to first experience what it means to be a WAPO Board member, e.g. workload, commitments and collaboration.

IT

Since 2019, WAPO has collaborated with the Dutch IT services company ‘Kwaaijongens’, specialized in ‘WordPress’ websites and M365 support.

Creative Designs

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

In 2025, the designers have supported us with the logo for the Blogs & Vlogs Series, update of our flyer and support to the Summit, with designs for banners, logo, ppt slidedeck, event app designs, update flyer, and much more.

WAPO ACTIVITIES IN 2025

8th Global Summit – October 10-11-12, 2025

In 2025 the WAPO Global Summit was held in Malahide, Ireland on October 10-11-12, 2025.

The Grant Hotel in Malahide was a very good, although more pricey, venue for the Summit. In Ireland, a large number of group hotels are booked for refugees or Ukrainian people, nor didn’t have the facilities we were looking for.

We were truly delighted when Dan Jeffries (Acromegaly patient – speaker – and more) accepted to host the WAPO Summit. Dan also prepared the AHA slides, for interactive questions during and in-between sessions. A new and extra item, which was very much appreciated by the patient advocates.

A total of **21** patient advocates from 18 countries were present, e.g. Chile, Australia, India, Taiwan and more. 12 presentations incl. 2 online speakers, and sponsor representatives were present as ‘observers’ and participated in the Industry Council meeting with the WAPO Board.

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

The 2025 Summit was made possible with the **Silver Level Sponsorships** by the following companies (in alphabetical order):

Camurus
Crinetics
ESTEVE
H. Lundbeck A/S

**IPSEN
Novo Nordisk
Recordati**

We like to express our gratitude to all pharmaceutical companies for their invaluable support and contributions during our meeting with the WAPO Board, as well as for their presence at the WAPO Global Summit program in 2025!

We thank all speakers for interesting presentations and their presence during the program. You will find the recorded presentations on the WAPO website: wapo.org/library

The WAPO Global Summit Program:

Friday October 10th Topics: :

- *FAETH, Awareness and Legal issues* by Margarita Amoroso Vasquéz
- *Approach care of patients with pituitary disease from diagnosis to treatment and follow-up - medical and surgical; incl. Q&A* by Mark Sherlock and Mohsen Javadpour
- *Arginine VasoPressin Deficiency – Outcomes HCPs survey* by Chris Yedinak

Saturday October 11th Topics:

- *Clinical Trials in a Nutshell: How Treatments are Developed and How Patients and Technology Can Shape the Future of Research Clinical Trials* by Daniela Shikova
- *The mechanism of visual impairment from pituitary lesions* by Lisa McAnena
- *The Orthoptist-led stable Pituitary Clinic* by Jaina Byrne
- *Understanding Self-Management and Adrenal Crisis Prevention in Adrenal Insufficiency: A National UK Survey* by Sofia Llahana
- *Psychological First Aid Kit for Patients with Pituitary Disorders: Practical Techniques for Emotional Management* by Max H. Almonacid Palacios
- *Introduction to CAMRare Patient Passport* by Jo Balfour
- *Early detection of acromegaly through AI assisted morphophenotypic tools* by Manel Puig Domingo
- *Can we do better to diagnose and control Acromegaly?* by Christine Yedinak
- *Patient-centered care* (online) by Noa Tal

Responses afterwards, via email and AHAslides

Patient Advocates:

"Excellent summit! Very well organised and coordinated"

"Great content, great food and great community!"

"Amazing few days. Massive thank you to everyone"

*"Meeting so many patient advocates and exchanging stories was fantastic!
There were excellent presenters with a wealth of information to absorb"*





Patient Advocates of Pituitary & Adrenal Patient Organizations, Guest Speakers and Industry Representatives

WAPO 2025 Blogs & Vlogs Series

Following the 2024's series, the WAPO Board also decided to organize a series of Blogs & Vlogs in 2025, with 6 topics. We again collaborated with Caretently Health Communications and for technical support with AVC Ltd, Ireland. And, like in previous years, we invited Patricia Vega to interpret and translate all information into Spanish.

WAPO especially wishes to thank the pharmaceutical company who supported us and made the '2025 Blogs & Vlogs Series' possible: IPSEN and H Lundbeck A/S and external parties.

Check out: wapo.org/library

Topics WAPO Blogs and Vlogs 2025

1. Workforce Participation: Opportunities and Challenges for People with Adrenal Insufficiency or Pituitary Disorders
2. Pituitary Gigantism: Acromegaly in Children and Adolescents
3. Changes in hormones and medication when growing older
4. Impact non-availability of medication for patients
5. Understanding Adrenal Insufficiency
6. Managing Pain and Sleep Issues in Pituitary and Adrenal Conditions

WAPO Awareness Activities

Creating awareness for pituitary and adrenal disorders is very important, due to the smaller concentration of people per country. The WAPO Board decided to reuse the 2024 campaign for Acromegaly, and create a new video for Cushing's. For Pituitary Month (October) and Acromegaly Day (November 1st) the Board decided to reuse the 2024 campaigns. We invited Natasha Barr (Caretently) to think with us. The following campaigns were defined:

1. Cushing's Awareness Day – April 8

WAPO invited patients and patient advocates to record their answers to a selection of questions, which were prepared by WAPO in collaboration with Dr Noa Tal (PNI, US).

We invited Dr Noa Tal to comment with specific medical information on each topic, which medical information is inserted in the video as well.

The Cushing's Disease Awareness video was a great success, with many views on the website and YouTube within 2 days. Participants came back with very positive comments, and were happy with the result of the video. We'd like to thank H Lundbeck A/S for their help and financial support.

Near April 8th, we learned about a new initiative to organize an Adrenal Insufficiency Day on April 7th, which we hope to support in 2026.

2. **Pituitary Month October:**

WAP0 reshared 4 infographic posters on 'Acromegaly, Cushing's, adrenal insufficiency and AVP-d' which were created in 2024. In all social media sources, these posters were very well reshared, in English, Spanish, French, German and other languages.

3. **Acromegaly Video** - November 1st:

In 2024, WAP0 created an Acromegaly awareness video 'Walk with WAP0 through the Experiences of People Living with Acromegaly' where patients and patient advocates recorded about their experiences during diagnosis and treatment.

WAP0 will reshare this video in 2025.

WAP0 also supported other Rare disease days:

Rare disease Day – February 28 2025

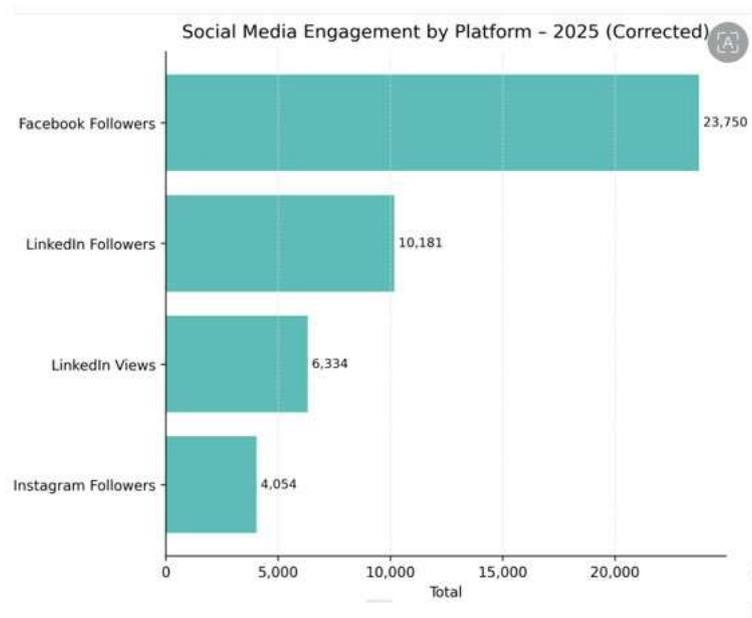
WAP0 shared the RDD toolkit, and also reshared and created several posts for this specific day for rare diseases.

Global Hormone Day – April 24 2025

WAP0 participated and reshared the ESE toolkit for 'Global Hormone Day' with member organizations. On April 24th, WAP0 promoted the Global Hormone Day and as many publications on social media as possible, and the ESE toolkit.

WAP0 Social Media Statistics

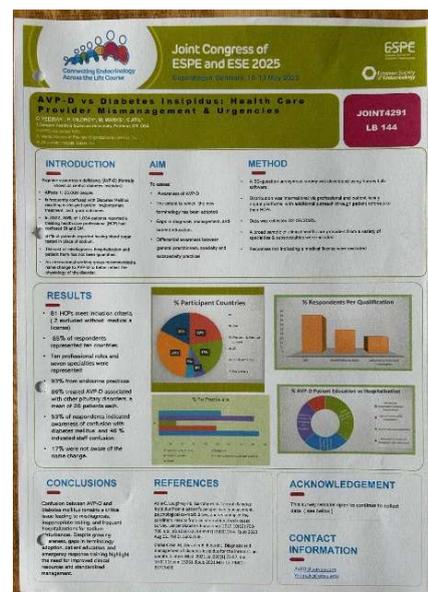
In 2025, WAP0 was present on various social media platforms, where we saw a rising number of followers and visitors of the website.



EXTERNAL PROJECTS

In 2025, WAPO participated in several external projects, organized by various stakeholders. Most agreements limit the sharing of details on the projects. Therefore WAPO will share general project information below:

- Co-creating a Cushing’s Disease survey | Reviewing outcomes (extended in 2026)
- Review a flyer for Cushing’s Disease
- Participation in a panel session with patient advocates, in Vienna, Austria (1,5 day)
- Participation in NAPA meeting (adrenal patient organizations Northern countries, 1 day), Copenhagen, Denmark
- Presence at ECE – ESPE 2025, in Copenhagen, Denmark (4 days)
Promoting: WAPO information, Acromegaly video on screen, disease awareness posters and WAPO visibility on poster with **‘AVP-d healthcare professionals survey outcomes’**
- Review part of research ‘Prolactin’ + reshare with WAPO Member Organizations + website;
- Project participation: develop ‘Guidelines Arginine VasoPressin Deficiency’ by Neuroendocrinology University of Basel, Switzerland, with 2 persons (partial; delayed till 2026)
- **Project participation:** Arginine VasoPressin Deficiency Survey for Health Care Professionals Collaboration with Pat Gildroy (‘Got AVP-D | Got DI?’ facebook group and Chris Yedinak (Mount Marty University; Medical Advisor to WAPO, US).



DATA & MAPPING

The WAPO Mapping Project III is scheduled for Q4 2025 – Q1 2026.

Currently we are adapting the questionnaire with WAPO Board and the company, which will follow up with interviews with the WAPO community, and their outcomes.

We thank IPSEN for making this possible.

In Q1 2026 we will start the interviews and will share the outcomes during the WAPO Global Summit 2026.

WAPO PARTNERS AND MEMBERSHIPS

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

In 2025 WAPO collaborated with the organizations and companies:

- * Adrenal Insufficiency United
- * International Consortium Adrenal Insufficiency
- * CAMRare – Patient Passport
- * European Society of Endocrinology (ESE) / European Congress of Endocrinology (ECE)
- * EURORDIS
- * FindMeCure | TrialHub
- * Federation of International Nurses in Endocrinology (F.I.N.E)
- * GAFPA (Global access for Patient Advocacy)
- * International Alliance of Patient Organizations (IAPO)
- * Latin Patient Academy (LAPA)
- * Patient Focused Medicines Development – PFMD and the Synergist, PEOF
- * Pituitary World News
- * Rare Diseases International
- * TouchENDOCRINOLOGY

WAPO Contact Information

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