

## **WAPO Activity Report 2021**

# WORLD ALLIANCE OF PITUITARY ORGANIZATIONS - WAPO 2021 ACTIVITY REPORT

## INTRODUCTION

WAPO activities in 2021 were still influenced by the Covid-19 pandemic, in several varieties, and disturbed all live meetings again. Per region this differed in the activities patient organizations could organize, and many of these events had to be virtually or were cancelled. Therefore WAPO chose to organize two eSummits, one in March and another one in October, to share information with member organizations, their members, caregivers and family, HCPs, Nurses and anyone with an interest in pituitary disorders.

Further, the WAPO Board chose a new chair – Sheila Khawaja – per May 2021. During the Annual General Meeting, the new ‘Medical Advisory Board’ was introduced, although the activities started in 2018 already, and the first advisors were welcomed by the WAPO members.

WAPO also carried out the 2nd Mapping Project to collect information from our member organizations to better represent them, to get better insight in their activities and issues they met. The outcomes showed interesting information, including the extra questions regarding Substandard Medicines. A topic to discuss further and to start-up a project about in 2022.

In the 4th quarter, many new ideas for 2022 were created of which we will inform you later.

We expect 2022 will be another active year, where we can meet again with patient advocates, Medical Advisors, speakers and sponsors. We really look forward to this!

The WAPO Board of Directors,  
December 2021

## WAPO Board of Directors

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

Mrs. Sheila Khawaja	Chair, per May 2021
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, 2021, the WAPO Board of Directors met via Teams in 16 Board and Strategy Meetings. In 80% of the meetings, all board members were present.

From September 2021 onwards, the Board decided to have an Executive Committee to proceed with daily activities, consisting of Sheila Khawaja and Muriël Marks.

In April 2021, the WAPO Board has decided to simplify the committee structure, which was used since May 2017. With the new structure, Board meetings are significantly shorter.

The new committee structure is as follows:

**1. Operations**

including: Daily business, Finances, IT, Summit | eSummit and Memberships.

**2. Awareness & PR**

including: Awareness campaigns (Cushing’s Day, Acromegaly Day, Pituitary Month, Rare Disease Day), Data collecting and Task Force.

**3. Communications**

including Blog and Communication campaigns.

**WAPO Member Organizations**

WAPO has welcomed one new member organization in 2021, the Pituitary Community Greece (September 2021).

On December 31, 2021, WAPO represented 41 patient organizations on Pituitary, Adrenal and Rare diseases.

**WAPO Medical Advisory Board**

Although we had no chance to formally introduce the WAPO Medical Advisory Board (MAB) in 2020, we are already collaborating with and consulting several of the following MAB members since 2018-2019. In 2021 the Medical Advisory Board was introduced during the online ‘Annual General Meeting’, where all members could present themselves.

Per 31 December 2021 the MAB is represented by the following health care professionals:

Chris 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

**OPERATIONS**

**Finances**

The WAPO Finance Committee consists of Muriël Marks, with support of an external, independent bookkeeper Mrs. J. van den Berg (Netherlands), who is available for questions and takes care of quarterly and annual financial overviews.

The annual WAPO Membership Fee of €35 was waived again in 2021 to support patient advocacies.

## 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'. In 2021 several adjustments were implemented on the WAPO website.

## Creative Designs

Since 2018 WAPO collaborates with the company El Cuore in Argentina.

For the WAPO eSummits they have designed logos, PowerPoint slide decks for presenters and the social media eBlast. WAPO also intends to continue working with El Cuore in 2022.

## WAPO ACTIVITIES IN 2021

### eSUMMITS

Due to the worldwide pandemic, WAPO organized in 2021 two eSummits, on March 19+20 and October 8+9.

For both eSummits, WAPO again chose to collaborate with Cello Health Communications (UK) as well as collaborating again with El Cuore (Argentina).

All speaker presentations were live interpreted during the sessions, by two EN-ES interpreters, with whom WAPO is working since 2018.

Afterwards, all presentations including Q&A session are made available on the WAPO website in English and Spanish (wapo.org).

#### Program March:

##### March 19:

*'Obesity, Nutrition and Diabetes incl. Q&A' by Prof. E. van Rossum (Netherlands)*

*'European Reference Centers + ENDO-ERN incl. Q&A' by Johan Beun (Netherlands)*

##### March 20:

*'Biosimilars incl. Q&A' by Dr. Anton Franken (Netherlands)*

*'Gonadal, Libido & Fertility incl. Q&A' by Javier Salvador Rodríguez (Spain)*

*'Pregnancy in Pituitary Diseases incl. Q&A' by Anton Luger (Austria)*

The March event was made possible with support of Recordati Rare Diseases, Pfizer, Ipsen, HRA Pharma Rare Diseases and StrongBridge Bio.

#### Program October:

##### October 8:

*'Management of acromegaly patients in the COVID era: impact on disease control and the role of telehealth incl. Q&A' by Dr Federico Gatto (Italy)*

*'Endoscopic approach to pituitary tumour resection incl. Q&A' by Dr Michael Cusimano (Canada)*

*'Pituitaries: Picture Perfect or Pathological? Incl. Q&A' by Dr. David Pettersson (USA)*

October 9:

*'Persistence of muscle weakness in patients with controlled acromegaly and Cushing's syndrome in remission. Mechanisms and role of physical activity incl. Q&A' by Dr. Elena Valassi (Spain)*

*'Building capacity for multi-stakeholder collaboration incl. Q&A' by Chi Pakarinen (Belgium)*

*'Adrenal Insufficiency, Covid-19 and Beyond incl. Q&A' by Dr. Chris Yedinak (USA)*

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

### **Annual General Meeting on May 29, 2021**

Due to the pandemic, the WAPO Board organized an online AGM, and asked all members to vote by proxy (via Survey Monkey). The Annual Activity Report and Finance overview was formally agreed upon and the board was discharged. During the AGM the Medical Advisory Board was also officially announced, welcomed, and each advisor briefly introduced themselves to the WAPO community.

### **WAPO Blog 'Global Pituitary Voice'**

In 2021 WAPO sent out 11 Blogs on various topics, which were all shared on the WAPO website first, and were also sent, using MailChimp, to all WAPO connections.

### **WAPO Awareness Activities**

'Awareness' is one of the key priorities of WAPO activities in 2021.

#### Rare Disease Day – February 28 2021

During Rare Disease Day 2021, WAPO mostly promoted member organizations' awareness campaigns and of third parties.

On February 26, WAPO Director Muriël Marks was invited by HRA Rare Diseases to share information on the impact of living with Cushing's, during an online meeting.

#### Cushings' Awareness campaign - April 8 2021

On April 8, 2021 WAPO collaborated with HRA Pharma Rare Diseases and Dr. Cornelia Andela (Leiden UMC, The Netherlands) in a webinar regarding:

'Understanding psycho-social challenges in people living with Cushing's Syndrome'

#### Pituitary Month – October 2021

WAPO contributed to Pituitary Month in the following activities:

1. eSummit on October 8 and 9 2021;
2. Launch of the educational and supporting 'Acroline Acromegaly series of 9 booklets' for patients, carers and HCPs; in collaboration with Pfizer;
3. Support to a 'Global Acromegaly Registry'.

## Acromegaly Awareness campaign – November 1 2021

The 2021 Acromegaly Awareness Day was really a special day. WAPO created 2-word clouds with Acromegaly related words, in English, Spanish and Russian. It was very well used, reshared, translated and logos were added.

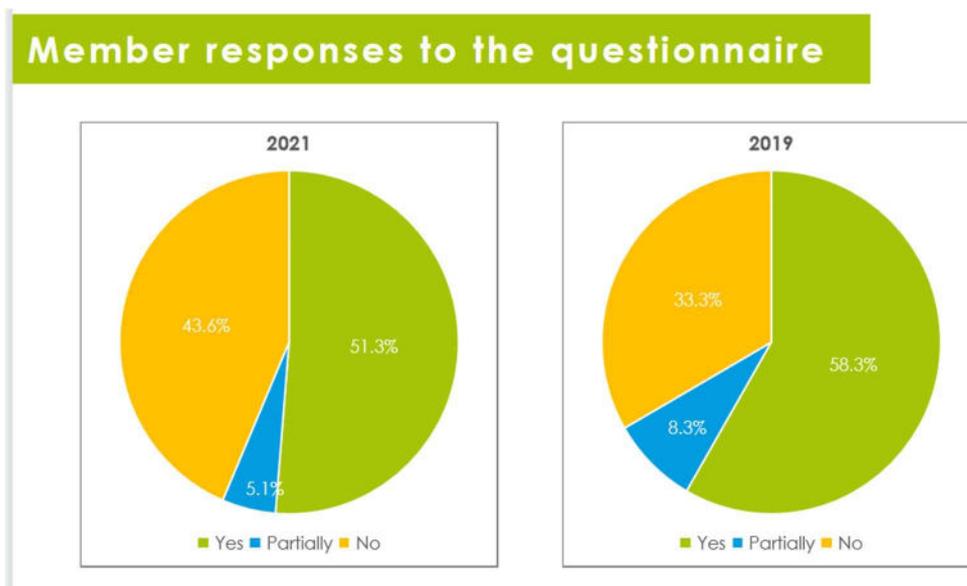
WAPO also choose to collaborate with the Spanish Acromegaly Patient organization, and translated their poster, which was also reused by several other organizations.



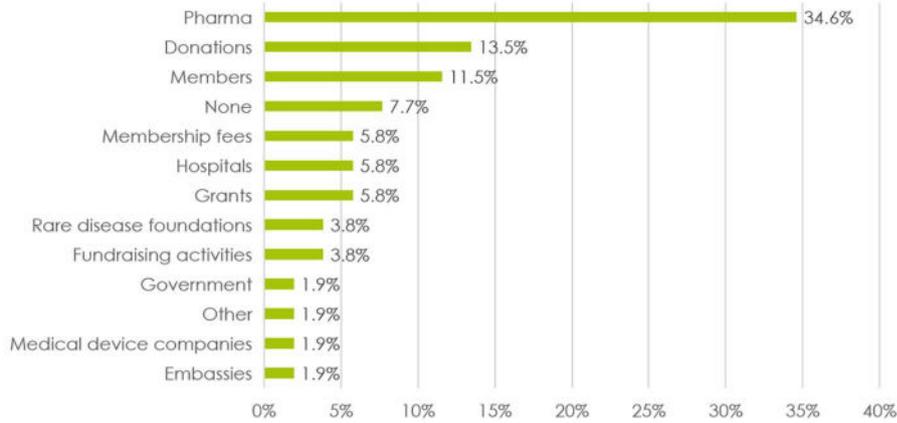
## DATA & MAPPING

In 2021, a new Mapping Project II was held during January – April 2021 and was carried out by Manuela Pelleri and her team (Argentina). They interviewed 22 WAPO member organizations, some of them already participated in the 2019 interviews. WAPO also requested information on ‘Substandard’ medicines and extra problems the patient organizations found during the Covid-19 pandemic.

The outcomes were presented to the WAPO community in an online Global Café session on March 23, 2021.

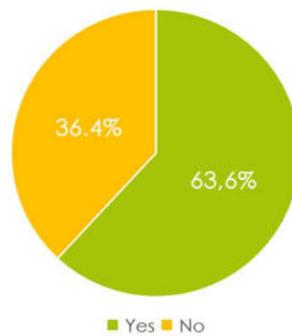


## Sources of income



Source: 2019 and 2021 studies

## Do you have a treatment guide?



Source: 2019 and 2021 studies

### WAPO AWARENESS PROJECTS September 2020 – December 2021

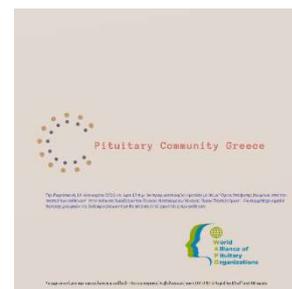
#### 1. Task Force - WAPO Best Practice & Project Funding

The Task Force, incl. the 'WAPO Best Practice & Project Funding' Committee, is founded to encourage and support member organizations during their activities, e.g. small projects, with which they could educate, train or improve support to their members, patients & carers.

The project especially focused on countries where government support is not available now. WAPO did receive 8 grant requests for financial support, but could only approve of 4 of them.

Approved projects between September 15 2020 - December 31 2021:

- a. 2020: Video Project with 6 videos in Spanish for Awareness of Acromegaly, by FAETH, Ecuador;
- b. 2021: Series of 10 supporting webinars by CORAPEHI, Chile;
- c. 2021: Legalization of Facebook group CDMX Acromegalia into a Patient Organization, Mexico;
- d. 2021: Support (financial + in kind) for organization of a very first educational patient meeting by the Pituitary Community Greece, Greece on January 14 2022.



## 2. Education

WAPO is keen to support patient advocates with education. Therefore we have offered patient advocates to follow the EUPATI Open Classrooms. After completing a course, at payment, patient advocates could apply for a certificate per course. WAPO paid for several certificates.

## 3. Knowledge support

Upon several requests from the community, the Task Force has supported patient organizations with information, medication availability, contact with government, supporting letters and more.

## 4. Website

On several occasions, the WAPO website had to be updated for a better performance.

All above mentioned projects were made possible with financial support by Recordati Rare Diseases and WAPO incomes.

## EXTERNAL PROJECTS WAPO PARTNERED IN

### **The World Rarest Dictionary**

In January 2021 WAPO was invited to join an online meeting to explain the concept of the 'rarest dictionary' as well as then developing a unique word (along with other patient organizations focused on pituitary disorders) as part of Rare Disease Day 2021. A number of words were proposed, and the committee selected 'Acromorphosis'. The project was developed by Ipsen. Visit <https://theworldsrarestdictionary.com/word-gallery/> to learn more.



### **ACROCOVID I, II and NORD**

The first global ACROCOVID survey was launched in 2020 due to the outbreak of the COVID19 pandemic to gather information from patients and healthcare professionals and understand how each group was handling, managing the lack of face-to-face appointments, delayed diagnostics exams, interruption of access to treatment and in many cases, postponed surgery.

The ACROCOVID I results were presented at the Patient HUB of the 2021 eECE online event. The outcomes were shared in a WAPO Blog including an infographic.

A second ACROCOVID survey was launched in early 2021 to verify or confirm any additional changes to the first results. ACROCOVID II was available in 5 additional languages besides English to increase the outreach. The poster was one of 7 nominated Top abstract submitted at the 2021 NORD Rare Summit held in October 2021 and we were given the opportunity to prepare a short 5 min. oral explanation to accompany the poster.



**Announcing the 2<sup>nd</sup> ACROCOVID Survey**

Revisiting our international assessment of the continuing impact of COVID-19 on the lives and care of people living with acromegaly

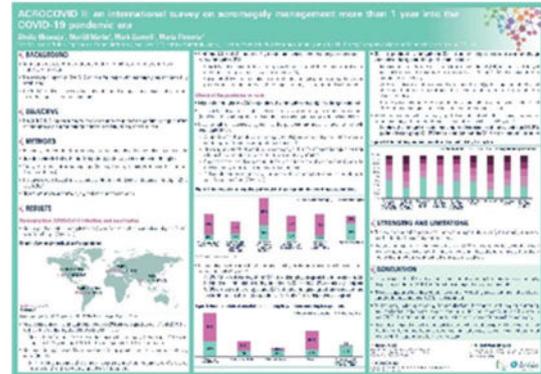
Available in English, German, Portuguese, Russian, Spanish and Simple Chinese

**Make Your Experience Count!**

pituitary connect  
Pituitary Connect is a global network of people living with pituitary conditions and their families.

World Alliance of Pituitary Organizations

Supported by an independent educational grant from Pfizer



### Acromegaly Global registry

In May 2021 WAPO was contacted by Pfizer to review a draft version of a global survey at the basis of the creation of a global acromegaly registry lead by Canada.

The collaborative project continued to the end of 2021 at which point the next steps need to be discussed with WAPO.

### Advisory Boards in 2021

WAPO, represented by Ms. Sheila Khawaja, Chair, has been involved in numerous advisory boards:

- PFMD Strategic Advisory Board
- Publication of Lay Summary – Patient editorial board as reviewer for Therapeutics in advancement of Drug Safety (SAGE)
- Member of the Plain Language Summaries Advisory panel at Future Science Group
- DIA Patient Engagement Core (PEC) Team member

## WAPO PARTNERS AND MEMBERSHIPS

WAPO is in partnership with many 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 new opportunities for our members. Most partners have organized virtual conferences in 2021.

### ADRENALNET – ADRENALS.EU

AdrenalNET is an online community for adrenal diseases, based in the Netherlands, mainly focusing and collaborating with European patient organizations.

In 2021 both AdrenalNET and WAPO collaborated in a new Spanish 'Cushing's Brochure', where WAPO organized the professional translation into Spanish of the earlier approved English version. Dr. Susan Webb (Spain) checked and approved of the translated version. When ready, the Spanish version of the Cushing's Brochure was shared via the WAPO Blog and website.

### ENDO-ERN

ENDO-ERN is the endocrinology section of the European Reference Centers. WAPO is interested in all news from ENDO-ERN (via Newsletter, LinkedIN, etc), and is also resharing information with member organizations via social media.

### EUPATI

In the last quarter of 2020, EUPATI launched the 'EUPATI Open Classroom' to enable patient advocates around the world follow the online course. WAPO encouraged patient advocates to join in the educational courses.

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

Like other organizations, ESE also organized an online eECE 2021, for which WAPO joined in the Patient Voice HUB. WAPO, represented by Sheila Khawaja (moderator), invited Dr. Chris Yedinak and Ewen Legg (COR2ED) to discuss and give more insights in the ACROCOVID II outcomes.

The screenshot displays a virtual conference interface. At the top left, there is a navigation link '< BACK TO LIVE STREAMS' and a viewer count of 'Viewers 103'. The main content area is divided into several sections:

- Video Feed:** Shows three participants in a grid. The bottom right participant is identified as 'Ewen Legg' with the role 'moderator'. The session title is 'The Patient's Voice 4 - Outcomes ACROCOVID I survey Acromegaly during the covid-19 pandemic'.
- Navigation:** Includes icons for 'Q&A', 'Polling', and 'Evaluation'.
- Poll:** A poll question is displayed: 'Would you - in future - consider collaborating with patients or patient organizations in medical research projects?'. The results are: A. Yes (100%), B. No (0%), and C. Other (0%).
- Supplements:** Includes buttons for 'Visit Company Profile' and 'Evaluation'.
- Session Title:** 'Session Title: The Patient's Voice 4 - Outcomes ACROCOVID I survey Acromegaly during the covid-19'.

In December 2021, the European Society of Endocrinology organized a meeting for patient advocates to discuss the upcoming 2022 ECE in Milan, Italy, in which WAPO joined. The ESE also opened the possibility for patient advocacies on a 'Patient Membership'. WAPO has applied for an official membership. Applications will be reviewed and followed-up by ESE in January 2022.

## **EURORDIS**

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 2021 and asked for suggestions on webinar speakers. Eurordis started in Q4 with the 'Eurordis Open Academy' to empower patient advocates with knowledge and skills to take part in patient engagement on a European and national level.

## **European Patients' Forum**

The European Patient's Forum (EPF) is an umbrella patient advocacy in Europe, an intermediary between the patient community and EU policymakers, by providing a cross-disease perspective based on issues regarding chronic conditions, which impact on patients' lives in national and regional context.

WAPO applied for a 'Full' Membership, but didn't fulfill the required number of 14 patient organizations in Europe. Now we have – temporarily – an 'Associate' membership. We also have had several calls to discuss mutual interests.

## **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. In 2021 we had several contacts, as well as discussions on reviewing their new product, which shows – all confirmed by industry - all available medicines per country in Europe, available only to industry. WAPO is discussing the availability for patient advocacies as well as extending outreach to other parts of the world.

## **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 is part of the WAPO Medical Advisory Board. She also organized a survey on 'Adrenal Insufficiency in relation to Covid-19' era, which outcomes were presented at the October 2021 eSummit.

Furthermore, FINE is collaborating in a video-project for the WAPO website, on video presentations of pituitary diseases, for people to better support and understand the written medical information. The project is expected to be ready in 2022 Q1-2.

## **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.

## **International Alliance of Patient Organizations**

In 2021 WAPO applied for membership of IAPO and was officially accepted as a full member in May 2021. WAPO deemed that the mission of the umbrella organization would be considered a valued collaborative partner in representing the voices of rare disease patients globally.

## Latin Patient Academy (LAPA)

Sandra Mesri (Argentina) is an active member of the Academy since 2019. She presented on March 6<sup>th</sup>, 2021, on 'How to work in a Collaborative Way'.

The present organizations are all focusing on the same conditions.

Sandra Mesri also joined the virtual CEPOF congress from June 21-23, 2021, a congress for rare diseases in Latin America.

Below Sandra will give an overview of key topics which were discussed during the 3-day meeting.

Topics discussed are:

1. General Practitioners: The importance of updating curricula was mentioned, as many of the diseases have only recently become known, so it is likely that if a doctor has been trained for some time and has not updated his/her knowledge, he/she will be unaware of these diseases. The importance of interconsultation with other specialists was also discussed.
2. Interdisciplinary group of doctors: The need to work in a group of specialists to see the patient as a whole and reach a diagnosis more quickly was discussed.
3. Rare diseases: It is estimated that there may be as many as 8000 rare diseases. 89.1% of rare diseases have a prevalence of less than 1 in 100,000. Almost all people with rare diseases (98%) have one of the 390 most prevalent diseases.
4. Orphanet: Presented their database which includes 70% of pediatric rare diseases and 72% of the diseases in its database are of genetic origin.
5. IRDIRC (International Rare Diseases Research: This organization proposed to carry out research on rare diseases coordinated between several countries to have a more representative number of rare diseases.
6. Target Therapies: The use of therapies for each individual patient is becoming more and more common, and this will be a challenge for the future. The person-centred model of care was discussed.
7. Medical omnipotence: patient associations argue that the omnipotence of doctors, especially in Latin America, should be ended and that we should move towards a model of working together in future, as patients have a lot to contribute.
8. Price of medicines for rare diseases: This issue has many edges and needs to be tackled from different sides. The government must seek and provide incentives for research into these diseases, otherwise no one will be interested in them. On the other hand, laboratories should make their production costs transparent to reach patients with better prices. How is it possible that a drug in different countries has such a big difference in price? It was also raised that the high cost of medicines could favor the national production of medicines.
9. Patients: the truth is that there is a long way to go, sometimes we feel that they use us and speculate with our interests. There is no patient participation in most of the working groups and it seems to be annoying that many patients have more information than the governments themselves about some pathologies. There is a demand for compliance with laws guaranteeing coverage of medicines, as well as non-interruption of medicines. While there is a lot of will, it does



**REUNIÓN DE TRABAJO - 2021**  
Para líderes de pacientes de Latinoamérica

**SÁBADO 6 DE MARZO DE 2021**

 Sandra Mesri presentará el Programa de mentoreo para la formación de alianzas regionales por patologías.

 David Peña, presidente de FEMEXER presentará el panorama de las patologías de baja incidencia en México y el trabajo de los pacientes.

ID de reunión: 867 0327 8354 / Código: 250683

HORARIOS	
9.00 HS	Costa Rica - El Salvador - Guatemala - Honduras - México - Nicaragua
10.00 HS	Colombia - Cuba - Ecuador - Panamá - Perú
11.00 HS	Bolivia - R. Dominicana - Venezuela
12.00 HS	Argentina - Brasil - Chile - Paraguay - Uruguay

not translate into participation or results. Patients waste a lot of time and money to obtain coverage for medicines that should be covered by the state.

### **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). 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. WAPO and PWN Blogs are regularly reshared on both websites.

### **International Society of Endocrinology (ISE)**

WAPO has been collaborating with ISE since mid 2019 on various occasions. In 2021 WAPO was represented in the ICE 2021 (February 21-24). Later WAPO joined in the Middle-East ICE 2021. WAPO was the only patient community represented. Currently we are discussing new – joint - webinars for 2022.

### **Real World Evidence 2022: Rare diseases and innovative Therapies**

In November 2021, Sheila Khawaja was invited by FSG to record a teaser video as part of the patient experiences ahead of the RWE event scheduled for June 2022 in London, UK.

The series of patient experience recordings, including WAPO's Chair is available [here](#).



### **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 January 2021, 2 Board members presented WAPO in a short video interview.

In 2020-2021, together with Eurordis and many rare disease patient communities, we discussed and collaborated with WHO, which finally resulted on December 16, 2021 in the formal adapted UN Resolution on “Addressing the Challenges of Persons Living with a Rare Disease and their Families”.

### **World Patients Alliance**

A non-profit community representing patients and patient organizations all over the world, focusing on all disorders. WAPO became a member in 2021.

## WAPO CONTACT INFORMATION

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**LinkedIn:** World Alliance of Pituitary Organizations

**Twitter:** [WAPO\\_org](https://twitter.com/WAPO_org)