



WAPO Activity Report 2019

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WORLD ALLIANCE OF PITUITARY ORGANIZATIONS

WAPO 2019 Activity Report

Introduction

WAPO activities in 2019 were focused on the priorities set at the 2018 and 2019 Summit: internal and external communications, awareness campaigns, best practice sharing, international travel letter, mapping project and Summit 2019.

In 2019, representatives of WAPO Member Organizations and the WAPO Board of Directors have spent many hours in making decisions, collaborating with pharma industry, connecting with new member organizations and two awareness campaigns.

Also in 2019, the mail and postal address have changed into Nonnenhof 4, 5411 BM Zeeland (NB), The Netherlands. Email and mobile numbers remained the same.

We are looking forward to the Summit 2020, our flagship event for the fifth time already, which will be held in Buenos Aires, Argentina from March 20-22, 2020.

During the Summit and AGM, WAPO patient advocates will set the targets for the upcoming year.

WAPO Board of Directors

From January 2019 till the Summit 2019, the WAPO Board of Directors consisted of

Mr. Andrei Andrusov	Chair / Treasurer (partial)
Mrs. Sheila Khawaja	Vice-Chair
Mr. Ernest Lundu	Treasurer (till February 2019)
Mrs. Muriël Marks	Executive Director/Secretary
Mrs. Malini Raj	Board member
Mrs. Sue Kozij	Board member
Mrs. Sandra Mesri	Board member
Mrs. Sonja Durinck	Board member (till April 2019)
Mr. Weiqiang Zhan	Board member (till February 2019)

In 2019 all Board members had to be (re-)elected after a 3-year period.

During the AGM on May 19, 2019 the following WAPO Board members were (re-)elected:

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

Based on the GoToMeeting records, the WAPO Board has met 15 times in Board meetings, which lasted for max.1,5 hours with 5-6 participating Board members each time.



Muriel Marks Netherlands	Andrei Andrusov Russia	Jorge Faccinetti USA	Sheila Khawaja Italy	Sue Kozij Australia	Sandra Mesri Argentina
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WAPO Board activities

The Committees established in 2017 are still active.

WAPO Board has the following committees:

- Finance Committee
- Fundraising & PR Committee
- Summit Committee
- Awareness Committee
- Membership Committee
- IT Committee
- Communications Committee including:
 - Internal Communications
 - Best Practices
 - Mentorship Team
 - Mapping Team
 - Surveys Team
 - External Communications
 - Newsletter Team
 - Awareness Team

WAPO Member Organizations

Per December 31, 2019, WAPO has 34 member organizations who are working in 29 countries. In 2019, WAPO has welcomed 7 new member organizations:

New Patient organizations in 2019:

- China Hypercortisolism Patient Alliance from China per January 2019
- Ausvis, Lithuania, per April 2019
- CDMX, Mexico, per April 2019
- Acro_Kasia - Stowarzyszenie Chorych z Akromegalia, Poland per April 2019
- Norwegian Morbus Addison Association, Norway per July 2019
- Ukrainian Pituitary Foundation, Ukraine, per November 2019

Associated patient organizations in 2019:

- Ottawa Awareness & Support Network from Canada, per November 2019

Resigned patient organizations in 2019:

Patient organizations who have resigned from WAPO membership:

- CPPN, Canada per March 22, 2019
- Glandula, Germany per December 31, 2019

ANNUAL SUMMIT & AGM

WAPO organized the fourth annual Summit from May 17-19, 2019 in Lyon, France at the Novotel Lyon Confluence.

The 4th WAPO Summit was special due to the collaboration with the European Society of Endocrinology (ESE), who held their ECE2019 in the same period (May 18 - 21, 2019) in Lyon, France.

During the overlap day of May 18, WAPO and ESE Nurses shared a program at the ECE2019 venue.

WAPO Member Organizations, speakers and sponsors travelled per chartered bus to the ECE2019 congress center, where we were welcomed with a lunch box and invited to mingle with endocrine HCPs. After this, the program started. Please find below the Summit 2019 program:

Friday, May 17:

- 14:00 Welcome & Introduction
- 14:10 Introduction by patient advocates and WAPO guests
- 14:30 Best practices by patient advocates
- 16:15 "How to effectively communicate with patients in difficult situations"
- 17:45 End of general program
- 19:00 Welcome dinner

Saturday, May 18:

- 08:30 Strategic planning for patient organizations by Kathy Redmond (Redmond Consulting)
- 10:15 "A journey through clinical research, working together to improve the experience" - workshop and practice by Rachel Jones (Swi.ch, UK)
- 11:40 **Departure by WAPO Bus to ECE2019 venue**
- 12:15 *Combined sessions with ESE Nurses*
- 12:15 Lunch WAPO & ESE Nurses
- 12:45 "Residual Morbidity and impact on QoL in pituitary disease" by Dr. Elena Valassi (Barcelona, Spain)
- 13:15 "Shared decisions and making the best of your consultations" by Sofia Llahana (Consultant Nurse in Endocrinology – London, UK)
- 13:45 Workshop "How to develop a researchable question?" by Ann Marland (Nurse Practitioner in Endocrinology - Oxford, UK)
- 15:30 What's new on genetic in pituitary conditions?
- 16:00 Presentation & Dissemination of 'WAPO Mapping project' incl. Q&A by Sandra Mesri (WAPO Argentina)
Adrenal insufficiency – medical by Chris Yedinak (Professor, OHSU Portland, U.S.A.)
Adrenal insufficiency – support by Johan Beun (AdrenalNET, Netherlands)
Requested support by patients by Muriël Marks (WAPO, Netherlands)

- 16:30 Group picture, Networking & Book launch
 17:00 *End combined session & Departure WAPO by bus*
 17:30 WAPO Members Pictures & Wrap-up
Sunday, May 19:
 09:30 Poster contest
 09:45 **Annual General Meeting** - only for full WAPO member organizations
 12:30 Farewell & Lunch

Hand-outs

- WAPO Collection of Best Practices
- WAPO Activity Report 2018
- Health trackers (FitBit)
- Awareness pins
- Color markers



Poster contest

The patient advocates brought along 18 posters on a 'best practices' and everyone could vote on each poster. Sheila Khawaja presented the first and second prize winners:

1. **Asociación Española de Afectados por Acromegalia** received the first prize: 'waiver of the attendance fee of €135 at the Summit in 2020' and a 'Certificate of Appreciation',
2. **Club Of Acromegaly Taiwan** won the second prize: 'waiver of the Membership Fee 2020 of €35' and a 'Certificate of Appreciation'.

Annual General Meeting

The Annual General Meeting (AGM) was held on Sunday, May 19, 2019, where only full member organizations were allowed to join and there was one vote per organization. This year all positions on the WAPO Board of Directors were to be (re-)elected.

Summit & AGM - General information

The 2019 Summit was attended by 19 WAPO full member patient organizations with 22 patient advocates. There were 4 guest speakers, 7 industry representatives ('observers') and 2 interpreters (English-Spanish). Eric Kozij supported the WAPO Summit and Kathy Redmond (Redmond Consulting) was our moderator for the Friday and Saturday program. During the Summit we showcased 2 WAPO Summit banners which included the logo of supporting pharma industry. Furthermore, WAPO presented three signs to take pictures with: the word '#WAPO2019', the pin and the word 'Pituitary' in several languages. This year we chose not to have a 'Social Media Wall'.

Newsletter 'Global Pituitary Voice'

The WAPO Newsletter 'Global Pituitary Voice' is a tool to spread knowledge and to keep in touch with our members. It keeps all patient advocacies and third parties up to date with what is happening in other countries and regarding pituitary condition diagnosis and treatment.

In 2019 the 'Global Pituitary Voice' appeared 4 times and was managed by Editor Sue Kozij, who is supported by graphic designer Ashleigh Glendinning (Australia). The final edition for the year was sent through 'MailChimp' to all mailing list subscribers.

The content varies, but always contains a 'Chair's foreword, a doctors' article, a patient story, projects by WAPO members and a Calendar with pituitary-related interesting events from around the world.

WAPO also collaborated with Pituitary World News (also a WAPO member) to share mutual interesting information to WAPO members.

WAPO Awareness Activities

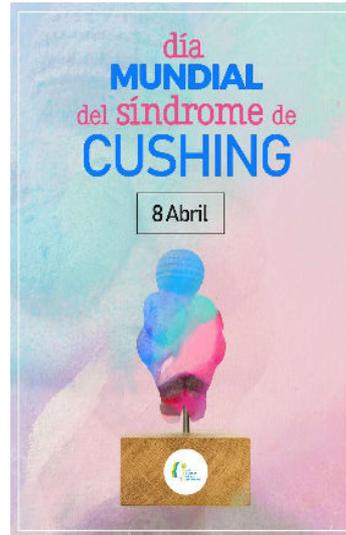
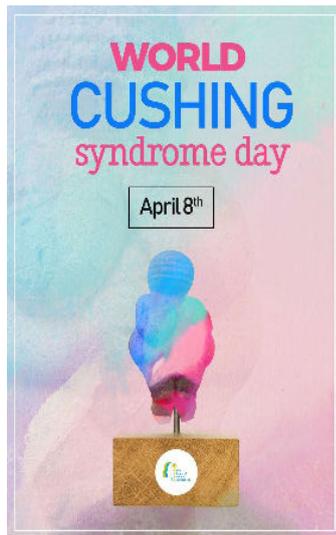
Awareness is one of the key priorities of WAPO activities in 2019. This year, patient organizations were offered a simultaneous global awareness campaign, which were shared in many ways. Our campaigns are designed with the participation of some patient groups from different countries, and material is co-created based on the requests received by the patient organizations.

Cushings' Awareness campaign

WAPO ran a campaign during the 'World Cushing's Day' on April 8, 2019.

The campaign poster (in English and Spanish) was shared by email to all WAPO member organizations and on WAPO's Facebook general page as well as the WAPO closed FB Forum Group. Over 8,000 people saw the Awareness poster.

The campaign was extremely successful and many professionals responded very positively as well.



'WAPO Pituitary Awareness' Pin

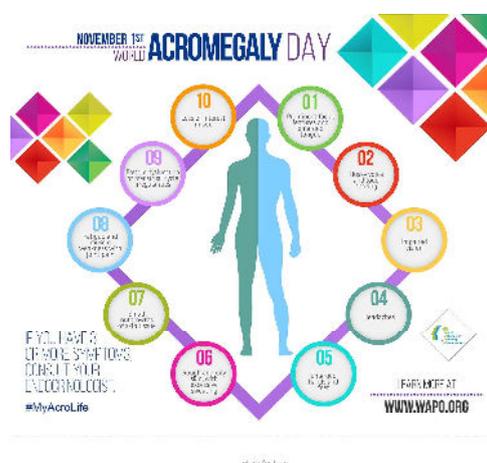
In 2019 only 500 pieces of the 'WAPO Pituitary Awareness Pin' were left. They were handed out at the WAPO Summit 2019, several international conferences and at ECE2019. There are no more pins left.

Acromegaly Awareness campaign

WAPO ran a new campaign during the 'Global Acromegaly Awareness Day' on November 1, 2019.

The campaign posters - general and symptoms - were shared in English and Spanish, by using email, WAPO FB General and closed FB Forum Group, Twitter, LinkedIn and website.

Member organizations were offered to have their poster translated in their own languages or add their own logo to the poster professionally, at WAPO costs. Besides English, the posters appeared in French, Lithuanian, Russian, Italian and Spanish. Five patient organizations added their logo to the English version. HCPs and pharma companies also shared the WAPO Acromegaly Awareness campaign. WAPO considered the campaign very successful. Following the global campaign, some organizations even shared the posters in hospitals.



MAPS

The outcomes of the WAPO Mapping Project, which started in November 2018 and went on till January 2019, were presented at the WAPO Summit 2019.

The project goals were:

1. Receive and update information of the WAPO Member organizations and receive additional information, etc.;
2. Receive information to create an overview of hospitals for treatment per country;
3. Receive information on medication availability per country.

The project was made possible with the financial support by Pfizer.

WAPO Partnerships and Relations

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 or even patient collaboration. Of course we will look for more collaboration in 2020.

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. EUPATI has a training facility on medicines development, clinical trials, medicines regulations, health technology assessment. Additionally, EUPATI offers and maintains the Toolbox on Medicine Development, and coordinates a network of national platforms for patient advocates. WAPO is receiving their newsletter and updates by email frequently, which is shared with WAPO member organizations too.

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

After the WAPO Summit 2019, Sheila Khawaja and Sandra Mesri represented WAPO for 2 days at the ECE2019 (May 20 and 21, 2019) in Lyon. They had a table stand, where information was shared and met with many HCPs.

Physicians and endocrine nurses frequently asked after the WAPO activities and over 90 persons completed the application form to receive the WAPO Newsletter.

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 bringing together all stakeholders and mobilising the rare disease community, EURORDIS strengthens the patient voice and shapes research, policies and patient services.

WAPO regularly receives their Newsletter and shares interesting information or opportunities to join webinars or meetings through the WAPO closed FB Forum Group.

ENDO-ERN

ENDO-ERN is the endocrinology section of the European Reference Centers. Some of WAPO members are involved in the ENDO-ERN.

WAPO received their regular Newsletter and shares interesting updates with WAPO member organizations via mail and Facebook. More selective information for WAPO members will be shared in the WAPO FB Forum Group.

In 2019 we also shared an ENDO-ERN general survey on 'Endocrine Diseases' with EU WAPO member organizations. In 2020 we will report on the outcome.

FindMeCure

WAPO got in contact with FindMeCure in 2017. FindMeCure is an organization which links the clinical research industry and the people looking for a new, alternative treatment. Since then we signed an agreement to become partners. Through a widget on the WAPO website, patients can search for new worldwide clinical trials on pituitary and adrenal diseases. During the WAPO Summit 2019 information on FindMeCure was shared.

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 was also involved in the collaboration of the WAPO Summit 2019 - Summit Team and the Nurses Pre-Meeting. Chris Yedinak accepted an invitation to join the WAPO Medical Advisory Board.

GafPA (Global access for Patient Advocacy)

Sandra Mesri (Argentina) was invited to the Academy representing WAPO. There were 3 meetings in person and some teleconferences made by GafPA.

Membership of GafPA is free and only upon invitation.

Participants are leaders from Latin-American regional patient organizations, and they participate in the Committee for Healthcare Technology including new Procedures (HTA).

Patient Focused Medicines Development - PFMD

While being in Brussels on February 13, WAPO took the opportunity to meet with Mrs. Harmoire, to sign - on location - the agreement to collaborate.

During this meeting, we discussed to share PFMD's 'The Pledge' poster and brochures during the WAPO Summit 2019 in May. This was very well organized by PFMD.

Publication of Lay Summaries (PLS) project

At the beginning of 2019 WAPO (Sheila Khawaja volunteered) was invited to take part in a new project run by PFMD concerning the publication of lay summaries of clinical trial results and general scientific research. In September PFMD organized the Patient Engagement Open Forum (PEOF) in Brussels to involve different stakeholders, including the general public to work on various projects, including PLS. Following the event, the team members implemented the notes and recommendations made by the participants to improve the draft version. The team met once again in November and is due to present the final version of the PLS toolkit and guidebook in June 2020 where WAPO will be presenting again.

Pituitary World News (PWN)

Pituitary World News is an online news website. By publishing information about what happens when the pituitary gland starts acting and how it affects people, they hope to increase awareness. PWN is founded by Dr. Lewis S. Blevins Jr. and J.D. Faccinetti in 2014. PWN is also a WAPO partner organization, which resulted in a section on the PWN website, called 'News from Around the World' to highlight member activities and collaborations. They designed this section to provide a platform for WAPO members to share their practices, ideas and innovations. The site is widely distributed through extensive SEO and social media platforms.

Jorge Faccinetti is also a member of the WAPO Board of Directors and joined several communications and Board teleconferences as well as attending the 2019 WAPO Summit.

Rare Disease International

RDI is a global alliance of people living with a rare disease of all nationalities across all rare diseases, It was originally established by EURORDIS, but is an independent NGO as of May 2018 when the Statutes were approved during the RDI Annual Membership meeting.

RDI brings together national and regional rare disease patient organizations from around the world, as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

WAPO receives their newsletter, mailings and invitation to join their AGM.

ISE – International Society of Endocrinology

WAPO met with ISE during the ECE2019. From that point on, the contacts became more intense and resulted in a supporting role and patient testimonial for the ISE webinar 'Adult GHD: An interactive debate about diagnosis, dosage and treatment' on December 13, 2019.



WAPO invited ISE to join the Summit 2020 in an educational role, and Pamela Funes, ISE education coordinator will be joining us at our 5th Summit in Buenos Aires, Argentina to do a training session on 'Patients and HCPs: An Informal Conversation and an Example of Collaboration'.

INTERNATIONAL MEETINGS & CONGRESSES

WAPO has become a well-recognized organization and is invited to projects and meetings, where the voice of the patient must be heard.

WAPO representatives have attended several international congresses to significantly increase WAPO's visibility and to meet with possible new sponsors, interested parties, etc.

EURORDIS 3rd Multi Stakeholder meeting - Brussels, Belgium - February 13&14, 2019

In February, Sheila Khawaja and Muriël Marks represented WAPO during the 3rd Multi-Stakeholders Meeting in Brussels, Belgium.

The topics of the presentations were interesting and different break-out sessions gave the opportunity to make the voice and importance of WAPO members heard.

Acromegaly Conference - New Orleans, U.S.A. - March 20-22, 2019

The Acromegaly Community Inc. organized their 2-annual meeting in New Orleans, at the same time of the Pituitary Society.

The program had very interesting speakers and on Friday morning, we could - for the first time ever - join the morning program of the Pituitary Society, where Jill Sisco and Daphne Adelman (also first time for the Endocrine Nurse Specialists!) presented on Acromegaly. Sue Kozij, Sandra Mesri and Muriël Marks represented the WAPO Board, upon invitation by Jill Sisco's Acromegaly Community Inc.

The attendance of Sandra Mesri and Muriël Marks was 100% sponsored.

ECE2019

WAPO joined the Pre-Nurses Meeting on Saturday afternoon, during the WAPO Summit 2019 program (see Summit 2019 section).

Sandra Mesri and Sheila Khawaja represented WAPO during the Sunday afternoon program, in a round table session with the nurses on Acromegaly.

On Monday and Tuesday they represented WAPO at a table stand with information on WAPO, the WAPO banner and giveaways like the Pituitary Awareness Pin and color markers. Approx. 90 ECE2019 HCPs subscribed to receive the Newsletter.



Cushing's Support & Research Foundation - 2019 Patient Journey Summit Atlanta, USA - October 4,5 and 6, 2019

WAPO joined the '2019 Patient Journey Summit' after invitation by President Leslie Edwin, who invited Muriel Marks to speak on 'Progress Out of Europe and Around the Globe', which included detailed information regarding Cushing's studies and activities by other WAPO member organizations.

Jorge Faccinetti also joined the meeting on behalf of Pituitary World News, which also gave an opportunity to discuss WAPO topics.

The Patient Summit was a great opportunity for WAPO to learn from CSRF's leaders and members and to share mutual ideas and ensure future collaboration.

World Drug Safety Congress - Amsterdam, The Netherlands – September 9-11 2019

Sheila Khawaja participated as a roundtable co-chair on patient engagement along with Matthias Boedding (Merck) and Rachna Bedi (Imperial College). There were almost 20 participants in the group (including Muriël Marks) who had a lively discussion on various aspects of drug safety and the value of involving patients in PV.

“A similar discussion was also held the following day and the two groups merged to provide a wider overview and discussion on the topic.



Some participants on the first day of roundtables



Rachna Bedi,
Matthias Boedding,
Sheila Khawaja

PEGASUS networking event - Leiden, The Netherlands – December 10, 2019

Sheila Khawaja was invited to participate and give a short 10 minute talk on the challenges and value of a global organization such as WAPO at the PEGASUS® networking event organized by admedicum. The informal event aimed at allowing multi-stakeholders to meet and discuss about the various aspects of their patient engagement – in this case, it focused on global organizations.

Following the event, Sheila was invited to attend the Patient Partnering in Clinical Development (PPCD) to be held in Berlin on March 2-3 2020.

WAPO Medical Advisory Board

In 2018 WAPO established a Medical Advisory Board. The goal of the MAB is to connect to HCPs and ask after their advice in case there are medical questions by member organizations. Several HCPs have accepted a role at the MAB in 2018 and 2019. WAPO has decided to officially present the MAB at the 5th WAPO Summit 2020 in Buenos Aires, Argentina.

Finances

In February 2019, Andrei Andrusov took over the role of Treasurer after the resignation of Ernest Lundu at the end of January 2019. Together with Muriël Marks they formed the Finance Committee. Mrs. Vania Dubrova joined the Finance Committee from November 2019, but was not active.

WAPO is supported by Trajectum (accounting firm) for financial reporting in 2019.

The 2019 Membership Fee amount of €35 per patient organization was continued and was collected together with the Summit Attendance Fee to save banking fees for the NGO's. In case NGO's did not pay their 2018 contribution, they had the option to pay the Membership Fee 2018 and 2019 together, possibly with their Summit 2019 Attendance Fee.

The Membership Fee is meant to support the WAPO Association.

The Attendance Fee for the Summit is meant to support the Summit organization and expenses.

WAPO received support from various pharma companies for the Summit and other activities,

including a donation from admedicum admedicum We are, of course, very thankful for these endorsements, which helped WAPO support patient advocacies around the world.

WAPO bought a PayPal license with which we could also create a 'donation button' on the website and plan to activate it in 2020

IT & SOCIAL MEDIA

In early 2019, the WAPO Board decided to end all existing contracts with website and email hosting companies, due to long-lasting website and communication problems.

From August 2019, we found a new Dutch company 'Kwaaijongens', specialized in 'WordPress' who took care of updating and supporting the WAPO website. They included a 'Password' section for Member Organizations, which also shares video presentations of earlier Summits and linked MailChimp for sending the Newsletter, etc.

The website was - as planned - 'ready and running' by December 31, 2019, although some texts still need to be updated.

This also meant several WAPO Board members had to (re-)start content management on the website and received some training to send out the Newsletter through Mailchimp.

FACEBOOK

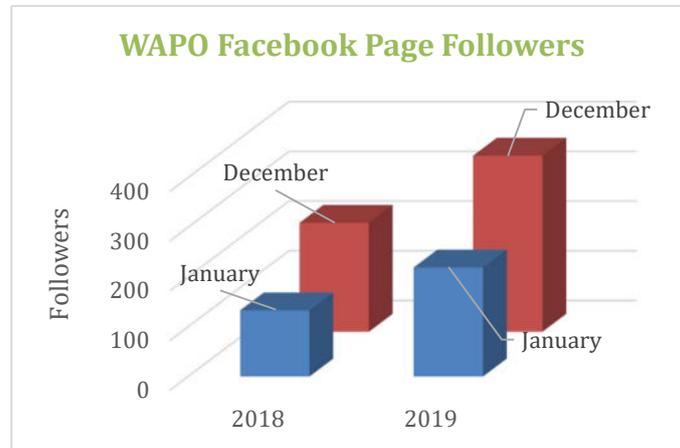
Social media is the channel where patients and patient groups share news, launch awareness campaigns and keep the community involved and informed.

The following is data gathered from January 1, 2019 to December 31, 2019 on the open WAPO Facebook page.

2019 followers



Looking back at 2018, data shows that there has been a 65% increase in followers from February (133 followers) to December (219); similarly, in 2019, the January followers began at 219 and jumped to 354 by December, representing another increase of 62%.



We also wanted to understand which posts had been the most visible over 2019 and set the minimum outreach benchmark for consideration at 400. Noteworthy is the astonishing difference in outreach of the Cushing’s Campaign on April 4th and April 8th.

DATE	TOPIC	OUTREACH
25.01.19	PWN – FAETH & CORAPEHI	809
04.02.19	PWN – Drug development news	635
21.03.19	Acromegaly Conference – New Orleans (hair and makeup)	1,000
04.04.19	Cushing’s awareness campaign	593
08.04.19	Cushing’s awareness campaign	7,800
18.05.19	Rachel Jones @ WAPO Summit	521
01.08.19	PWN – Cortisol matters	903
27.10.19	Acromegaly day campaign	448
29.10.19	Vancouver acromegaly – I love someone rare pin	803

Post Details

WAPO
Published by Muriel Marks-de Korver (7) · 8 April 2019

April 8th is a special day for us!

WORLD CUSHING syndrome day
April 8th

cushing's syndrome
- symptom -

Performance for your post

7795 People Reached

170 Reactions, comments & shares

93 Like	17 On post	76 On shares
15 Love	1 On post	14 On shares
6 Sad	1 On post	5 On shares
14 Comments	2 On Post	12 On Shares
42 Shares	42 On Post	0 On Shares

579 Post Clicks

418 Photo views	1 Link clicks	160 Other Clicks
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NEGATIVE FEEDBACK

2 Hide post	0 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

Post Details

WAPO
Published by Muriel Marks-de Korver (7) · 4 April 2019

April 8 - World Cushing's Syndrome Day ...
Please support the WAPO Awareness Campaign and share the poster ...

WORLD CUSHING syndrome day
April 8th

día MUNDIAL del síndrome de CUSHING
8 Abril

Performance for your post

593 People Reached

46 Reactions, comments & shares

29 Like	9 On post	20 On shares
3 Love	2 On post	1 On shares
0 Comments	0 On Post	0 On Shares
14 Shares	14 On Post	0 On Shares

32 Post Clicks

13 Photo views	0 Link clicks	19 Other Clicks
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NEGATIVE FEEDBACK

1 Hide post	1 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

WAPO CONTACT INFORMATION

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LinkedIn: World Alliance of Pituitary Organizations

Twitter: [WAPO_org](https://twitter.com/WAPO_org)