



2019 SUMMIT REPORT

**World Alliance of Pituitary Organizations
(WAPO)**

Lyon, France – May 17-19, 2019

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Background

History

In October 2014, it was agreed upon to start a new, independent non-profit global network of pituitary patient organizations. The goals were to improve communication between patients and healthcare professionals, start a global awareness campaign and survey to collect patient experiences to use as an advocacy tool at a national level. Gaps in diagnoses, treatment and care of patients with pituitary conditions were also highly ranked.

Since this decision was made, the Board of Directors worked on the establishment of the World Alliance of Pituitary Organizations, in short 'WAPO' which became an official entity on May 30th, 2016.

WAPO General facts

- First meeting held in 2012.
- Legally established since 2016 in Amsterdam, The Netherlands.
- WAPO currently has 36 member organizations from 27 countries, amounting to 38% of global population (thus more than 290,000 pituitary patients potentially represented).
- WAPO member organizations have 15,000+ pituitary patient members.
- WAPO Board has 6 directors from 6 countries: Australia, Argentina, Italy, Netherlands, Russia and U.S.A.
- In 2018-19: Board members held 92 e-meetings lasting 73 minutes on average with 5 attendees on average, and 506 manhours total.
- Communication media: www.wapo.org, Facebook, Twitter, regular Newsletter, mailings, annual Summit and AGM.

WAPO's mission is to identify pituitary patient advocacies and guide the development of their organizations as well as creating an active global network

We believe that the strength of a global network of national pituitary patient organizations will lead to improved diagnosis, treatment and care for pituitary and adrenal patients worldwide.

We will consider our mission completed when the patient declaration* is fully implemented in all countries.

*Patient declaration was drafted and first signed in Zurich in 2012 <http://www.wapo.org/patient-declaration/>

WAPO Target Groups

WAPO has identified several target groups which it seeks to support (directly and indirectly) through its activities and initiatives.

Target Group	WAPO's Role/Objective
Patient Advocates / Patient Organization Leaders and Their Teams	To assist Organizations and empower them to bring about new implementations at national scale and get actively involved in international co-operation
Patients	To assist patients in getting earlier diagnoses improve access to optimal treatment and care
Clinicians And Other Healthcare Professionals	To educate clinicians to trust patient advocates and collaborate among themselves and with patients
Other Patient Organizations, Professional Associations, Rare Disease Associations, And Other Partners	To facilitate learnings from pituitary patient organizations, encourage collaboration and networking
Researchers (Basic Scientists, Pre-Clinical And Clinical Studies ²)	To provide incentives to increase research and listen to the patients' voices
Pharmaceutical Companies (Business Development Leaders, Patient Relations)	To advice pharmaceutical companies reach their goals and provide patients with more affordable and high-quality drugs
Healthcare Decision Makers (Authorities Of All Levels, Insurance Companies)	To facilitate decision-makers reach their goals while listening to patients' voices
General Public	To ensure the public is aware of pituitary conditions and supports patient advocates

WAPO's Value for Patient Advocates

- Independent global non-profit organization uniting pituitary patient organizations creating a global voice of patients in global and national policy making.
- The point of concentration of correct, evidence-based information on pituitary and related diseases.
- The center of best practices of pituitary advocacy organization and operations.
- The driver of global pituitary awareness activities.

WAPO's Value to Pharma

- Fight for approval of all necessary drugs in all countries and access to quality treatment.
- Provide patient view on existing drugs and other products for patients.
- Increase awareness to foster early diagnosis.
- Ensure publicity, incl. at special events like Pituitary Month, Acromegaly or Cushings' day.
- Co-create and provide expert advice on clinical trial design

The Benefits of Full Membership

- An international community of similar patient organizations represented in over 24 countries.
- Access to a vast base of experience and knowledge of dealing with major issues every pituitary organization faces around the world.
- Constant and quick support, as different organizations are in different Time Zones, your question will not remain unanswered. You can contact other members via personal emails or via our Facebook page.
- Access to a library with major documents on different languages (i.e. official documents, requests to authorities, grant requests and many more).
- An ability to contact other organizations and doctors with broad experience who can help your patients with advice.
- International support to your organization.

WAPO Progress 2018-2019

During 2018, we made significant progress centered around some key focus areas

- Summit
- Awareness
- Capacity building
- Internal communications
- External communications
- Membership data
- Operations

Please see Summit Activity report (APPENDIX) which was also distributed to all delegates during the Summit and details Activities for 2017 and the key elements of progress.

WAPO Memberships 2016 - 2019

	2016	2017	2018	2019
Organizations	14	25	32	36
Countries	13	23	24	27
Approximate total population represented	862 million (12%)	2 596 million (35%)	2 716 million (36%)	2 921 million (38%)

WAPO Summit 2019

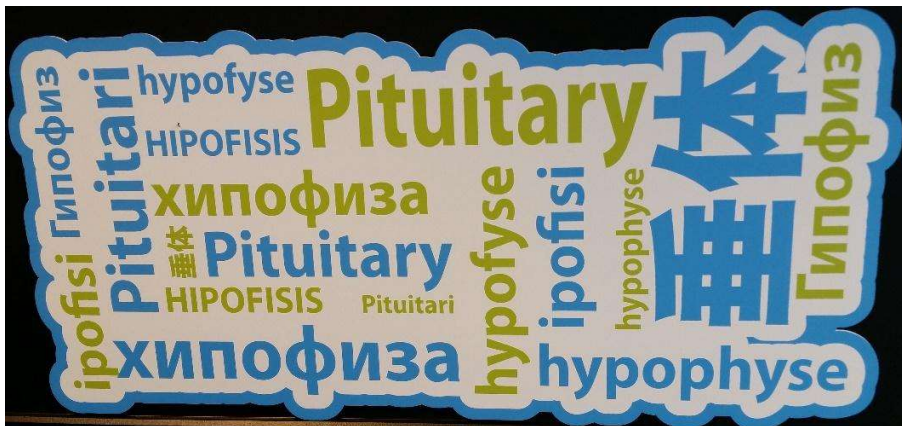
The Agenda

The 2019 Summit was organized in Lyon, France in order to collaborate with the Nurses of the European Society of Endocrinology during the ECE2019 in Lyon (May 18 – 21, 2019).

WAPO organized the program for Friday and Saturday morning at the Novotel Lyon Confluence, while the joint session was held from 12:00 (incl. lunch) – 16:45 at the ECE venue.

The joint program was prepared and discussed during the period of July 2018 – April 2019.

WAPO focused this year on ‘health’ related topics, like the ‘fitbits’ which were handed out and sponsored by ‘RecycleHealth’ (U.S.A.).



This year Kathy Redmond facilitated the Summit program on Friday and Saturday, both at the WAPO venue as well as the ECE venue. The Sunday AGM was facilitated by Sheila Khawaja.

Also the ‘Guidebook’ app was prepared for all Summit participants and it included the agenda, Who’s Who details, supporting information on the hotel, weather, travel and other supporting information.

WAPO invited again the two interpreters Marta Brotto and Alessandra Maggiora to come to France, in order to provide a high quality of dual translation in Spanish – English.

The WAPO guests received a printed version of the ‘WAPO Activity Report 2018’ and ‘WAPO Collection of Best Practices’ and a WAPO-branded marker (triangle form) and 2 ‘Pituitary Awareness pins’.

Presenters and subjects WAPO Summit 2019

Friday, May 17:

- 14:00 Welcome & Introduction - Andrei Andrusov - Chairman
- 14:10 Introduction by patient advocates and WAPO guests
- 14:30 Best practices by patient advocates (4-5 presentations)
- 15:45 Coffee break
- 16:15 Workshop by Mrs. Karen Powell (Cancer Support France, Languedoc) on
"Silence, tears and challenging statements: Techniques to support clients in distress and to look after yourself while you do"
- 17:45 End of general program
- 18:00 WAPO Board meets with pharma representatives
- 19:00 Welcome dinner

Saturday, May 18:

- 08:30 Strategic planning for patient organizations by Kathy Redmond (Redmond Consulting)
- 10:00 Coffee Break
- 10:15 "A journey through clinical research, working together to improve the experience" by Rachel Jones (Swi..ch, UK)
- 11:30 End morning session
- 11:30 Departure from WAPO to ECE2019 venue by bus
- 12:00 Lunch (WAPO participants arrive by bus to ECE2019 venue)

12:50 Welcome and meeting objectives
Sofia Llahana, ESE Nurses Chair
Andrei Andrusov, WAPO President
Alexandrine Bost, French Nurses Group Chair

13:00 Session 1: Presentations followed by a Q&A session Chairs: Andrei Andrusov, Elena Shelestova and Alexandrine Bost

13:00 Residual Morbidity and impact on Quality of life in pituitary disease
Elena Valassi, Consultant Endocrinologist (Barcelona, Spain)

13:25 Shared decisions and making the best of your patient consultations
Cecilia Follin, Endocrine Nurse Practitioner (Lund, Sweden)

13:50 From question to evidence: developing a research or audit question and conducting projects to evaluate your practice or organization

Anne Marland, Nurse Practitioner & PhD Researcher (Oxford, UK)

14:15 Coffee/tea break and networking

14:45 Session 2: Developing a consensus for patient education and standards care services for patients with Adrenal Insufficiency

14:45 Therapeutic Education of Patients with Adrenal and Pituitary Disorders: the French initiative by Alexandrine Bost and Brac De La Perrier (Lyon, France)

15:05 Adrenal insufficiency in patients with pituitary and adrenal conditions and evidence of impact of patient education

Christine Yedinak, Professor of Endocrinology Nursing (Oregon, USA)

15:20 Patient perspective: primary adrenal insufficiency

Johan Beun, AdrenalNet (the Netherlands)

15:30 Patient perspective: secondary adrenal insufficiency in pituitary conditions

Muriël Marks – WAPO (the Netherlands)

15:40 Developing a consensus for patient education and standards for care services for patients with adrenal insufficiency: an international collaboration

Sofia Llahana, Consultant Nurse in Endocrinology, ESE Nurses (London, UK)

16:00 Open discussion and Q&A on Consensus proposal and next steps

16:30 Conclusions and take home messages

16:45 End combined session & Departure WAPO by bus

17:30 WAPO Members – Voting for posters

19:30 Dinner

Sunday, May 19:

09:30 Poster contest

09:45 Annual General Meeting

12:30 Farewell & Lunch

13:30 Meeting New Board

Pictures WAPO Summit 2019





WAPO Poster Competition

WAPO asked all participating patient organizations to prepare a poster on a special best practice initiative of their patient advocacy.

We received 15 posters, which were voted on by all patient advocates.

Sunday morning all votes were counted and Sheila Khawaja presented the two entries which received the most amount of votes were the

1. Asociacion Española de Afectados por Acromegalia
2. Club of Acromegaly Taiwan (COAT) (2nd)

Both winners received a certificate with the following information:

1st place: Waiver of €135 Attendance Fee Summit 2020, picture and article on the poster in Newsletter

2nd place: Waiver of €35 Membership Fee 2020, picture and article on the poster in Newsletter.



WAPO Summit Attendees 2019

The WAPO Summit was attended by 22 patient advocates, 19 organizations, and 17 countries.

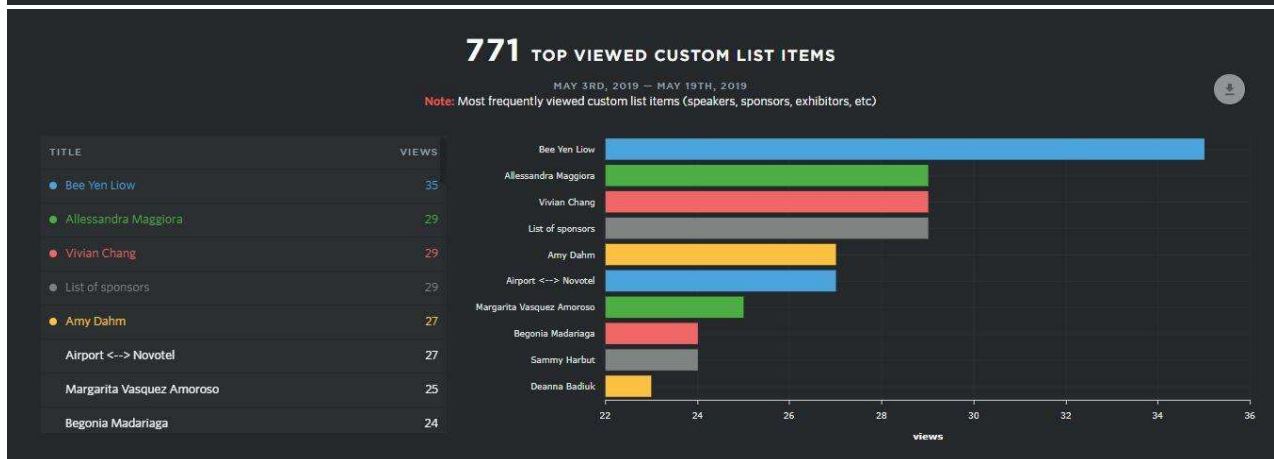
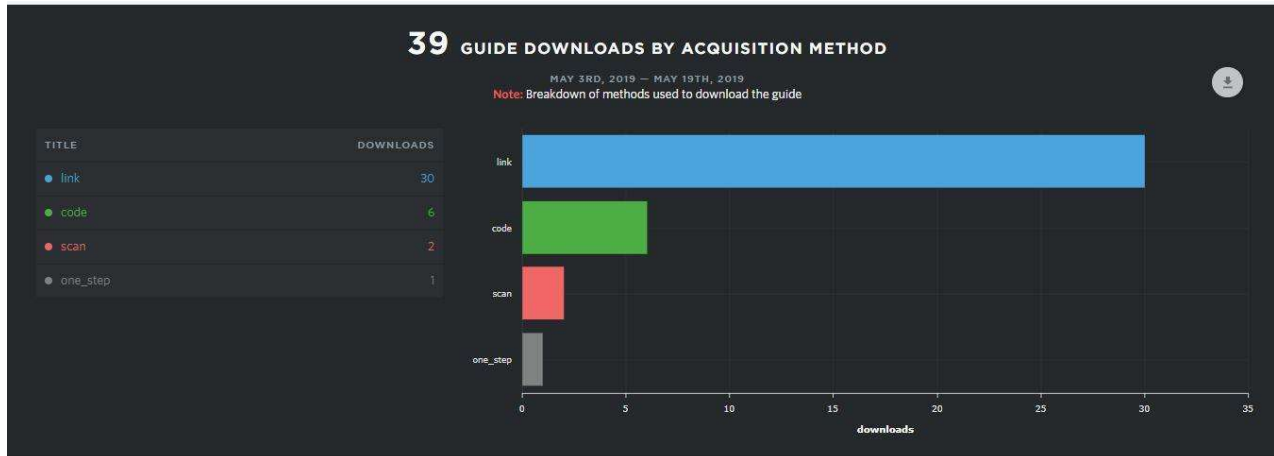
There were 4 speakers, 1 moderator, 2 interpreters and 7 sponsor representatives.

Collectively they represent a population of 2,9 Bn people.

Based on estimates of the amount of Pituitary patient sufferers per 1 million people in the general population, it translates to over 290 000 patients.

USE GUIDEBOOK APP

Also in 2019 the Guidebook app was used for information on beforehand and during the WAPO Summit 2019. We noticed there was a stark increase in the number of users of the app, indicating that our members are gradually 'warming' up to its use. We expect to use it again in our 2020 summit. Please find below some statistics.

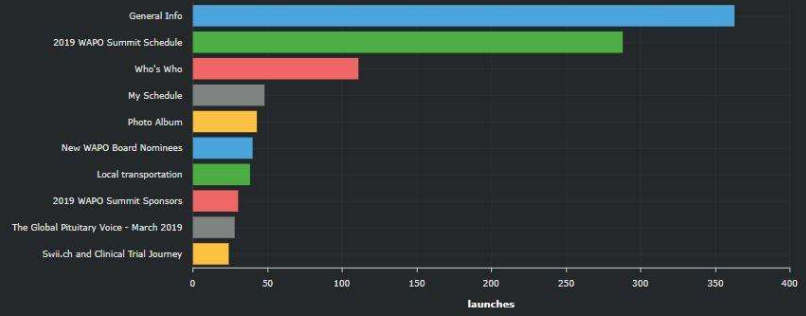


1,144 TOP MENU ITEMS LAUNCHED

MAY 3RD, 2019 — MAY 19TH, 2019

Note: Most frequently launched guide menu items

TITLE	LAUNCHES
General Info	363
2019 WAPO Summit Schedule	288
Who's Who	111
My Schedule	48
Photo Album	43
New WAPO Board Nominees	40
Local transportation	38
2019 WAPO Summit Sponsors	30

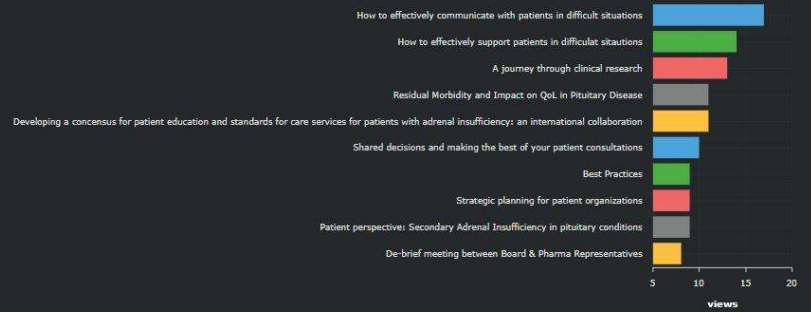


224 TOP VIEWED SCHEDULE SESSIONS

MAY 3RD, 2019 — MAY 19TH, 2019

Note: Most frequently viewed sessions in your schedule

TITLE	VIEWS
How to effectively communicate with patients in difficult situations	17
How to effectively support patients in difficult situations	14
A journey through clinical research	13
Residual Morbidity and Impact on QoL in Pituitary Disease	11
Developing a consensus for patient education and standards for care services for patients with adrenal insufficiency: an international collaboration	11
Shared decisions and making the best of your patient consultations	10
Best Practices	9
Strategic planning for patient organizations	9



WAPO AGM 2019

Election of the WAPO Board of Directors

In 2019 the 3-year term of the Board members expired. All went for re-election except for Malini Raj, due to lack of time. Furthermore, Jorge Faccinetti showed interest to join the WAPO Board, since he already worked with the board in the Communication Committee for a year.

All nominees were approved of for another 3-year period by the Full Member Organizations.

The following members were elected as Board Members for 2019-2022:

Name	Country	Position
Andrei Andrusov	Russia	Chairman
Sheila Khawaja	Italy	Board Member and Vice-Chair
Muriël Marks	Netherlands	Board Member and Secretary
Sandra Mesri	Argentina	Board Member
Jorge Faccinetti	U.S.A.	Board Member
Susan Kozij	Australia	Board Member

WAPO Member Organizations 2019 per May 15, 2019

Organization	Country	WAPO key contact
APEHI Argentina	Argentina	Sandra Mesri
Australian Pituitary Foundation	Australia	Malini Raj
Asociación Española de Afectados por Acromegalia	Spain	Raquel Ciriza
Club of Acromegaly Taiwan (COAT)	Taiwan	Vivian Chang
Bulgarian Association of Patients with Acromegaly (ABAB)	Bulgaria	Dimitar Stoyanov
Bulgarian Pituitary and Adrenal Association	Bulgaria	Vania Dobрева
Vancouver Acromegaly	Canada	Deanna Badiuk
China Acromegaly Patient Association	Peoples Republic of China	Haining Wei
CORAPEHI	Chile	Max Almonacid
Asociación Todos Unidos Enfermedades Raras Uruguay	Uruguay	Maria Fonsèca
Association Surrénales	France	Joëlle Souche

Organization	Country	WAPO key contact
Acromégales ... pas seulement	France	Maité Dubois
Glandula – Pituitary & Adrenal	Germany	Helmut Kongehl
ANIPI Italia	Italy	Fabiola Pontello
Velikan	Russia	Katerina Andrusova
Esperantra	Peru	Karla Ruiz de Castilla
Hypofysenetvaerket	Denmark	Yelva Bjørnholdt Jensen
Swiss Support Group for Pituitary Gland Diseases (Wegweiser)	Switzerland	Karin Schäfer
My Acro	Malaysia	Muzamir Mohamad Nasir
Bijniervereniging NVACP (Dutch Adrenal Society NVACP)	The Netherlands	Muriël Marks
Pituitary Community South Africa	South Africa	June Mokoka
Pituitary Foundation UK / Ireland	UK / Ireland	Sammy Harbut / Niall Cavanagh
Asociación de Enfermos con Trastornos Hipofisarios	Ecuador	Margarita Vásquez
Acromegaly Community	USA	Jill Sisco
Cushing's Support and Research Foundation	USA	Leslie Edwin
Pituitary Network Association	USA	Jackie Hubbard
Pituitary World News	USA	Jorge D Faccinetti
Hormones411	USA	Sharmyn McGraw
Magic Foundation & ICOSEP	USA	Mary Andrews
The New Zealand Acromegaly Society	New Zealand	Catherine Chan
APADON	Brasil	Djanete Macêdo
CDMX	Mexico	David Gomez
China Hypercortisolism Patient Alliance	China	Jianmin Chen
Asociacija Ausvis	Lithuania	Danutė Puchova - Ledniovė
Acro-Kasia	Poland	Katarzyna Marcinkowska

WAPO Summit Sponsors 2019

The WAPO Board of Directors wishes to thank all Summit sponsors for their financial and in-kind support and their effort to help WAPO and the 2019 Summit be so successful.

Without your help, WAPO would not be able to support and create more awareness and opportunities for the Pituitary Patient Organizations.

We would like to extend and develop these relationships in 2019-2020 and look forward to discussing involvement and attendance in Summit 2020.

Thank you!

Platinum		
Gold		
Silver		
Bronze		

WAPO's Presence at the ECE on May 20 -21, Lyon - France

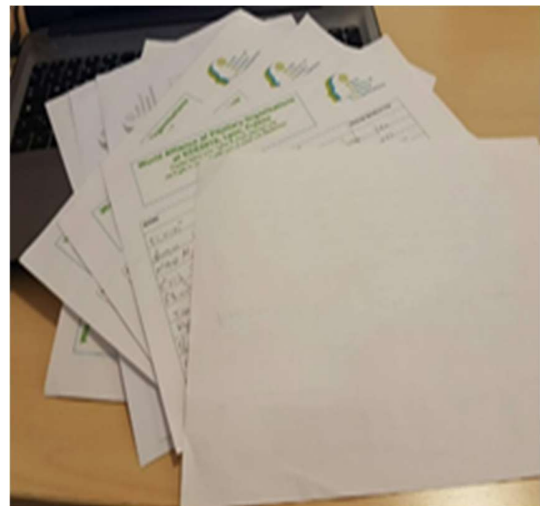
As in 2018, WAPO was also an active patient organization in a dedicated area of the ECE exhibition area along with 7 other organizations. We were able to set up our table on Monday as we had been busy with the organization's flagship event and a very intense collaborative session on Saturday afternoon at the pre-congress nurses' session.

Over the 2 days we met many endocrine experts, young researchers and nurses from all over the European region, including experts from Bulgaria, Romania, Greece just to name a few. Many had never heard of us and after a brief explanation, they signed up to receive our quarterly newsletter. Almost 90 ECE participants signed up – that is 32 more than last year, when we were in Barcelona! While we were at our desk, we also had the pleasure of chatting with Dr. Robertas Knispelis from the Lithuanian University of Health Science, like we did last year! It was fantastic to meet so many experts and to be able to interact with them – even if very shortly, as they were stopping at our table as they moved from one lecture to another. The participants who were most curious were those from Eastern Europe, but we also met doctors from Argentina, Malta, Tunisia, Jordan, Morocco, Brazil and also Philippines!

We consider our second 'stand' participation extremely successful and cannot wait to share with our new followers the latest WAPO Newsletter!!



Dr. Robertas Knispelis, Sandra Mesri & Sheila Khawaja



New Newsletter subscriptions

WAPO 2019-2020 Plans

Following the 2019 Summit & AGM, held a short strategy meeting to determine the following activities. The outcome was to proceed with the activities as presented during the Summit & AGM. After a short time two board members had to leave for a workshop with the ESE Nurses and the meeting was closed.

Details of plans will be developed by the assigned Board members in due course. Regular Board meetings will be held to discuss and develop the next Action Plans.

Relevant sub committees and areas of responsibility have been allocated to develop and execute plans. 2018/2019 Committee structure will be created.

Summit Committee	Muriël, Sue, Sheila, Sandra
Awareness Committee	Sandra, Raquel, JD
Capacity Building Committee	Andrei, Sue <ul style="list-style-type: none"> • Best practices – Andrei • Mentorship – Andrei • Webinars – ?
Internal Communications Committee	JD, Sue, Sheila <ul style="list-style-type: none"> • Newsletter – Sue, JD, Muriël • Social media – Sheila + all board members • Website – Sheila, Sue, Sandra
Finance Committee	Andrei, Muriël, Vania
Membership Committee	Muriël, Sue
External Communications Committee	Sheila, Muriël, Malini, Sandra <ul style="list-style-type: none"> • Europe/Intl – Sheila • Central and Eastern Europe – Andrei • South East Asia – Sue • Asia – ? • Africa – ? • South America – Sandra • North America – JD
Data	Sandra, Andrei, Muriël

In the coming year we propose the following activities under each focus area:

Summit	<ul style="list-style-type: none"> • Summit 2019 • Summit report, Summit feedback collection • Summit 2020 • Selection of the place (Vancouver/Buenos Aires) • Summit planning, preparation, organization • Fundraising
Awareness Committee	<ul style="list-style-type: none"> • Rare Disease Day (Feb 28 2020) • Cushing's day (Apr 8 2020) • Pituitary month (Oct 2020) • Acromegaly day (Nov 1 2020)
Capacity building Committee	<ul style="list-style-type: none"> • Best practice collection • Mentorship/twinning program • Webinars • Resource library • Travel letter (more translations)
Internal communications Committee	<ul style="list-style-type: none"> • Integrated communications via all channels (Facebook, Twitter, Newsletter, Summit) • 4 newsletters with a theme • Member restricted access to some materials within the website
Finance/Operations	<ul style="list-style-type: none"> • Policies • Accounting, Management accounting • Regular reporting • 2020 budgeting and 2019 reporting • Insurance, Bank • Consolidation 2 legal entities • Audit
Membership Committee	<ul style="list-style-type: none"> • Continue to expand awareness and increase membership
External communications Committee	<ul style="list-style-type: none"> • Continued activities with key stakeholder partners/sponsors • Continue to attend relevant events and explore speaking/panel and presentation opportunities in Europe, South East Asia, Asia, Africa, Americas
Data	<ul style="list-style-type: none"> • Mapping project Phase II (with data from countries missed in the mapping project) • Mapping project results publication • Global Quality of Life survey

WAPO contact information

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