

THE GLOBAL PITUITARY VOICE

JOURNAL FROM WAPO
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OUR VISION

The international pituitary patient community unites to combat stigma, promote early diagnosis and push for optimal treatment and care for all patients with pituitary conditions worldwide.

OUR MISSION

Combine our strengths to improve the diagnosis, treatment and care of all pituitary patients worldwide.



CHAIRPERSON'S REPORT

Dear WAPO members and friends,



Here is the first WAPO Newsletter in 2018. Most of this Global Pituitary Voice is about **awareness campaigns**. Awareness activity was named one of the key priorities of WAPO at the Summit 2017. This year we made our first attempt of a global awareness campaign. We learned a lot from it as well as from our members who have done a great job in awareness campaign planning, fundraising, implementing and reviewing. End of February is very rich in awareness activities as all the world heads towards the Rare Disease Day.

The newsletter starts with a very brief scheme for identifying and measuring **the impact** a patient organization makes on the world. Please see it as a guideline, a template to apply to your organization. It requires some time and teamwork to get to make the scheme work for you. As an example, you will see how this logic can be applied to an awareness campaign. Reading the rest of the Global Pituitary Voice from the angle of impact analysis is a very fruitful practice. I will be happy to discuss this approach at the Summit which we will have in April.

You will see more details about **the Summit** in this newsletter. This year we have it in Venice, Italy. As you can see it on page 27, the program is very intense but there still is space for Wellbeing and Mindfulness. We look forward to it!

In an article by J D Faccinetti (Pituitary World News) you will see the **awareness activities planning process** which includes a deep analysis of the target audiences and messages you want them to get through all the channels. Think about the brand!

Deanna Badiuk (Vancouver Acromegaly Support Group) has shared with you her story of the **patient group start up** and its success in hosting the first Acromegaly Conference in Canada. Several more stories from all around the globe revealed for you the peculiarities of patient organizations' activities at national and international level. There are things to "copy with pride" as we usually say!

Please pay attention to the feature article on **post-operative follow up**. To improve patients' lives after the first treatment, they must monitor their health regularly. It is important to share this information with all your members and healthcare specialists.

And – **the calendar** – as usual is a tool to help you choose all the right events to take part in. And please let us know if you spot one we have omitted.

Let us know if this issue is useful for you and your organization, and share it with your members, colleagues, partners, volunteers, friends and all those who care.

Andrei Andrusov: WAPO Board Chair

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SOCIAL IMPACT OF A PITUITRY PATIENT ORGANIZATION

Andrei Andrusov, WAPO Chair

Preamble

At WAPO, we are all pituitary patient organizations. No matter where we are or how small or big we are, we all need to have a clear understanding of what social impact we want to make. This is crucial for both external and internal communications. Indeed, our partners and sponsors are more likely to support us if they clearly see how our goals match theirs, and our team and volunteers are happier to spend their time and energy if they feel the intent and the good cause.

Let's try to reveal and analyze a patient organization from this point of view. This analysis can be used as a framework for your organizations reflection on its purpose and impact.

Key problems

Patient organizations are created because of the problems patients are facing. They can vary slightly from country to country, but for pituitary patients they are:

- 1) late/wrong diagnosis,
- 2) limited/no access to the right treatment and
- 3) quality of life issues after treatment. Quite clearly, the acuteness of these problems varies a lot from country to country and even between regions in some countries.

The purpose of a patient organization is to reduce these problems. In an ideal future these problems will not exist and there will be no need for patient organizations at all. The mission statement of a pituitary patient organization could be "to strive for early diagnosis, access to the right and timely treatment and better quality of life of pituitary patients in the country."

Problem tree (causes and effects)

To understand the way our advocacy impacts the patient community and the society in general and to plan the activity of a patient organization, it is important to build a tree of problems which will consist of the key problem(s) and their causes and effects.

Causes of late diagnosis include "the disease is rare, so nobody recognizes its symptoms", "the symptoms are not specific", "lack of specific hormone tests", "limited access to diagnostics (MRI, labs...)", etc. Causes for bad/inappropriate or no treatments can be: "late diagnosis", "limited access to good specialists (endocrinologists, neurosurgeons...)", "right drugs unavailable on local market", "pituitary related issues not covered by insurance/state support", etc. Some of our activities can focus not on the key problems but on their root causes.

Consequences of the key problems are "disease progressing", "patients suffering, low quality of life", "early invalidation and death of patients", "hardship and extra effort of caregivers", "doctors feel frustrated", "burden on national economies". Understanding the consequences is important to prove the activities are worth the effort to those not directly related to the pituitary diseases, for example governments.

Target groups

Talking about social impact is closely linked with the target groups whose life is impacted by our activity. For a patient advocacy typical target groups are: patients, caregivers, healthcare specialists, healthcare system officials (local, national and global), officers of businesses (drugs and equipment producers and distributors), patient organization staff, volunteers and donors.

When listing the target groups, it is important to identify people (not organizations), and their specific roles. Even though we can try to impact a pharma company in a way, interests of a product manager or a patient relation manager could be different, which make them different target groups.

Outputs, outcomes and impact

Patient organization's activities are aimed at impacting lives of people in the target groups. It is a good exercise to specify the effects on every target group. The effects can be structured into 7 levels:

Activities: what is done for the target group. "We want to run patient schools in our city every 6 months".

Outreach: how many people are affected by our activity. "More than 100 patients will come to our patient schools".

Feedback: how target group perceives our activities. "Most of participants of our patient schools say it was useful and informative".

Understanding: what new knowledge and skills gets the target group. "Participants of patient schools learn about their rights and possible legal actions they can go for".

Behavior: what the target group **does** differently. "Several patients actively fight for their rights after they participate in our patient schools".

Quality of life: what really changes in the target group's life. "Due to the legal action patients get the right treatment on time".

Societal change: what changed in the society. "Patients become active members of the society and proactively involve others in change-making activity."

Levels 1-3 are called Outputs and most of social projects do not go beyond these when setting their targets and reporting their activities. Levels 4-6 are usually referred to as Outcomes. And it is Level 7 (societal change) that an organization is ultimately aimed at. It is the impact.

Activity revision

Having listed the outputs, outcomes and impact of our activities, it is time to think again about our activities. We can now answer in a very clear way **why** we spend our time as well as the time of volunteers and partners and money of sponsors.

Do the activities really lead to the outcomes we have specified? Do they do it the most efficient way? What should be changed in our approaches, methods, communication channels, etc.?



Let's take an awareness campaign as an example. How does it change patients' quality of life? We believe that general awareness fosters (self-)diagnosis of pituitary patients, therefore reduces average time required for the right diagnosis. Can we really prove it does?

Social impact measurement

It is not enough to list the effects we want to reach. It is important to set specific targets and regularly monitor our organization performance in terms of these targets.

Measuring Outputs is relatively easy and still we often forget to record all the activities, numbers of people reached and their feedback in a structured and comparable way.

Measuring Outputs and Impact (changes in people's knowledge, skills, behavior and quality of life) is way more complicated. There are several ways to do it, here is a very short list:

We start with the simplest thing: **cases**. We identify people within our target groups who have experienced the expected changes and write the story down in a structured way. An open question in a feedback form (eg. "What did you learn at our patient school?") provides us with great stories about how life of our target group has changed.

Second, we collect opinions of **experts** on how our activities impact people's lives.

To be even more rigorous, we run **surveys** to collect quantitative data. It is a separate science, how to ask the right questions in the survey to get the evidence of the changes, how to run the surveys and how to make sure the responders represent the target groups we need.

The most persuasive, especially for scientists and government officials, are randomized controlled trials (**RCT**). It is when we compare the quality of life (or a more specific parameter) of two parts of our target group: those affected by our activity (e.g. participated in patient school) and those not affected (e.g. not participated).

To make sure we collect necessary evidence of efficiency and effectiveness of our activities, it requires a lot of attention at the stage of planning and a lot of rigor at the stage of implementation. And it is worth it. If done properly, it helps us prove that our activities do lead to reducing the acuteness of the key problems.

Tool for improvement

Why do we spend time doing all this? To be persuasive when raising funds, making a call for action at an awareness campaign, looking for volunteers and partners and building the team.

Another reason is that this approach helps us make our organization better. Let's take the same example of an awareness campaign (same steps can be applied to any specific activity we plan). We need to clearly understand what problem we want to solve with this campaign, what outcomes we want to achieve, what the ultimate impact is. We can set goals at any level of impact. And at every level there will be very good questions that can reshape the activity or even to stop it.

Let's say, we want 100,000 people to learn about the symptoms of the disease. It is level four effect. A metric here could be the number of people reached by the campaign on social networks. But have these people

really **learned** about the symptoms as we set in the goal? To check this, we can compare the real awareness before and after the campaign through specific survey.

Number of people who shared the message on social networks reflects an outcome of the fifth level as it shows how many people acted to share this information with others. But can we really be sure that they have acted consciously? Did they get really **involved**? Another level five goal is to bring many newly diagnosed pituitary patients (or just suspects) to doctors. What can be the best way to measure this result? Maybe doctors can count new self-diagnosed visitors and send us this information. Are they ready to do this? Will they be happy if there are more false “self”-diagnoses?

Increase in number of people righteously diagnosed and treated is a very good target and metric at level 6 of impact. Even if we know how to collect the data and data shows there was an increase, the question of attribution is always difficult: how can we prove that the increase was **caused** by our awareness campaign?

Conclusion

All the process of clarifying the impact of a patient organization may seem very complicated and long. Trust me, it is not. A 2-3-hour discussion with our key people and stakeholders can help a lot in making your work for the patients more effective. It is very useful to have this discussion every once in a while, for example, annually, to check that all the participants are synchronized on the organization’s mission and the activities are in line with the mission.

If you have not done it yet, try structuring your activity with this prospective in mind. I will be happy to hear how you use this approach in your organization’s daily life or what other tools you use for impact measurement and management.

WHAT SOME ORGANIZATIONS ARE UP TO

Traditionally, here is some news from our members from all over the world. We would like to thank those who responded to our request to keep us informed on what your organization has been up to since the Summit.

Send us your news to share your worries and hopes and best practices with colleagues from other countries.

Hopefully in our next newsletter we will have further information on activities in other countries.



UNITED STATES OF AMERICA

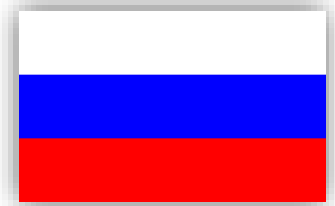
With the success of our social media frames from our Acromegaly Awareness day, November 1st, we decided to have patients use these again for rare disease day, February 28th. They say that a picture can speak a thousand words and for many patients with acromegaly, this is the case. We have urged the patients in our group to post side by side, pre-diagnosis photos and a current photo with treatment along with a short blog regarding the condition and the difference that earlier diagnosis can make. We want to make a real difference for others and are believers that someone might notice the subtle changes in themselves and seek medical advice.

Acromegaly Community has recently been working with a steering committee for our next conference. We are working on the planning and fundraising for the event. We will provide as many scholarships as possible and hope that patients from around the world will attend, just as they have in the past. We believe that educating the patient regarding acromegaly helps the patient to advocate for themselves. Our advocates tend to have a better quality of life than the typical patient and are taught about the disease and treatments from top experts in the field. We have speakers that consist of Endocrinologists, Neurosurgeons, Psychiatrists (pain specialists), rare disease counselors, Endocrine Nurses, etc.

Acromegaly Community will soon reach the 2000 member mark. Although we hate that we have to have a "rare disease" group, we are thankful to have a safe place to discuss our issues openly and thankful for the new acromegaly family that has been made. We cannot change the direction of the wind, but we can adjust our sails to always reach our destinations.

“My profile picture is of the same person. No cosmetic surgery. The light blue was taken in 2005 right before diagnosis, the dark blue was taken recently. I am not in remission but I am a patient that is biomedically controlled through meds for my acromegaly. I do everything I can to help give myself the best quality of life as possible. No one asks to have a rare condition that affects every aspect of their lives. Let me ask you a simple question; Has your shoe size increased or your ring size over the past few years? If the answer is yes; Do you think you might have some pituitary issues, such as swelling, sweating, joint aches, and headaches? If this answer is also yes, have you noticed a change in your appearance? Have you noticed your facial features coarsening? If your answer is yes, then you should consider seeing an endocrinologist that specializes in Pituitary disorders. I’m doing this because if I can help even one person that is suffering get diagnosed sooner, it typically increases the chances of successful treatment. Rare disease day is February 28, please help spread the word that acromegaly exists and that with treatment, life can be better for patients.”





RUSSIA

In December 2017 Velikan, the Russian pituitary patient organization, has launched a new project “Information and legal support to pituitary patients in Russia”. The project is co-financed by the President’s grant foundation and private companies. 1,5M₽ (21 500 EUR) were allocated from the foundation to Velikan to help and support people suffering from pituitary diseases.

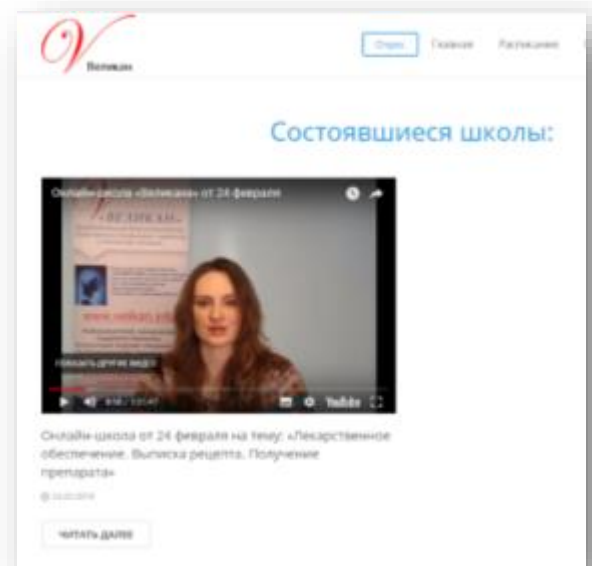
Today, in Russia, in each of the big cities, there are more than 250 patients with acromegaly and Cushing’s syndrome. Most of them are treated; some have troubles to get the right treatment. And very often, they do not receive timely information about their rights and opportunities.

The project’s goal is to help people, talk about their opportunities and rights to free medicines, to provide social assistance and legal support. But most importantly, to form the backbone of people united by the problems. We create an information space - forums, online schools where patients communicate with each other, share experiences and support each other. We plan to create a bundle "Patient – Lawyer – Specialist" – to help everyone in getting individual support, starting from assistance in document processing, ending with getting numerous benefits. Many patients simply do not know how to identify the disease and where to go with their problem. We make every effort to help all the patients.

During the year, monthly online schools for patients will be held (link). Live patient schools will also be organized in Rostov-on-Don, Novosibirsk and Moscow.

We have launched a new landing page (online.velikan.info) dedicated to the project and patients can now register for the webinars at the landing page. We have published several articles regarding the project and the pituitary diseases in regional and federal media.

The first online school took place on the 24th February. Patients from all parts of Russia (from Vladivostok and Norilsk to Moscow and Saint Petersburg) and even from abroad joined the webinar. Olga Bezborodova, the key lawyer supporting Velikan, talked about medicine prescription process and its current difficulties. She described the necessary formal legal procedures to get the medicines if regular ones do not work.





ARGENTINA & SPAIN

For the first time, the Spanish Association of Affected by Acromegaly and the Pituitary Alliance of Latin America made a joint action of awareness on acromegaly.

For the Rare Diseases day, on February 28, the two entities have decided to create a campaign in which, involving all of our patients, we want to make acromegaly known. Following the line of the video promoted by Eurordis, under the claim of #ShowYourRare, we thought about generating a similar action in Spanish, so that all the Spanish-speaking countries would join. We have titled the campaign #MuestraTuCambio #showyourchange

To carry it out we made a small video tutorial in which Sandra and Raquel as responsible for the two corporations, and some of our partners painted colors "acro" parts, any area of the body that the acromegaly had changed. Thus, many of them marked the hands, the feet, the nose, the forehead, the jaw and the tongue. A fun action that, shared in social networks we intend to generate impact and help to disseminate information.

Thanks to WAPO for letting us know. Hopefully this is the first of many joint actions, to which the rest of the WAPO members can add.



Raquel Ciriza

Sandra Mesri



"Sensitization of the Dentist and his contribution in the Early Diagnosis of patients with possible acromegaly"

Introduction

We are aware that for the sensitization of health professionals we must rely on entities as the dental school of Lima, which has more than 15 thousand dentists affiliated, through the video of broadcasting in its virtual platforms.

The present broadcasting work with the testimony of a patient, finds that dentists can focus their diagnosis of skull facial alterations and dental malocclusions by knowing the cause, as it is the case of acromegaly, making a consultation with the endocrinologist, and can thus reach a diagnosis that often takes up to 10 years to get to the final diagnosis.

So that patients may take actions regarding the medication, allowing them to not reach the cases where skull facial malformations are evident and something worse as damage to the organs and the growth of the upper extremities- lower, being the patient diagnosed in time we can contribute with their quality of life.

Objective: Is the sensitization of the dentist for the early Diagnosis in patients with possible acromegaly.

Methods:

1. video: testimony of a patient who went to consult split dentistry dealt with a problem of dental malocclusion and there was where it was determined the presumptive diagnosis of acromegaly by the professional treating. <https://we.tl/qMtUtKYL93>

2. face-to-face meeting in the Auditorium of the College of dentistry for the official presentation of the video directed to dentists, patients and interested.

Goal: With the video on the virtual platforms of the College of dentists in Lima. It is estimated to reach via. -Email to 15 thousand dentists - Facebook 50,000 - 10,000 website dentists.





CANADA

We had a huge awareness day for Acromegaly on Nov 1st in Canada. The objectives were to connect Canadians living with Acromegaly, raise awareness and educate on the disease, and engage patients in supporting other patients.

We worked with a media company and picked acromegaly advocates (people who are vocal on the Facebook pages and those that we know that bring a lot of awareness for acromegaly). We only had a month and a half to bring it all together but we all nailed it via. the News on TV in a lot of provinces, Facebook, twitter and write ups in local papers in most provinces. We also had an article written in the Huntington post for all of Canada.

We rocked it for 3 days straight.

The results for this day of awareness was that 5.1 million people in Canada saw or read or heard about Acromegaly.

Additionally, we were also able to get the Province of British Columbia Government to approve for the second year of Acromegaly Awareness Day! More work needs to be done to have it recognized Nationally for all of Canada, but this will take a big effort.



THE CREATING OF THE VANCOUVER ACROMEGALY SUPPORT GROUP & HOSTING THE FIRST ACROMEGALY NATIONAL/INTERNATIONAL CONFERENCE IN CANADA THIS YEAR

Deanna Badiuk – President & Founder of the Vancouver Acromegaly Support Group

I wanted to share with you all how I got started and how starting the Vancouver Acromegaly Support Group lead to us hosting the first Acromegaly Conference in Canada.

Six years ago, I started my journey for starting a support group in Western Canada for Acromegaly. I wanted to meet another person with acromegaly just to talk to but got told from my endocrinologist that this was not possible due to patient confidentiality restrictions in Canada. This very much upset me and thought this was not right. So, I told my endocrinologist that I was going to start a support group in Western Canada so we had support and could meet other Acromegaly people.

I started by writing up a hello letter of who I was and wanting to start a support group and put my email address on the letter and then printed it out and gave it to my endocrinologist to post in her office and to hand out to other acromegaly people. I also requested to have it sent to other leading acromegaly endocrinologists in Western Canada. A year later I had received 5 email requests to join. In April of 2013 we had a gathering in a restaurant for meeting each other at lunch, there were 5 members and 2 spouses that attended, and the excitement was overwhelming.

Since then we moved forward with having 2 meetings a year, spring and fall. I bring in specialists of all degrees that treat acromegaly people to do presentations on what they do to help us and how we can take care of ourselves better. As the meeting came up more people joined with their partners or support person. It was in the beginning of the second year that I realized that we needed a board to become a legitimate non-profit organization. With the organization of a board and moving forward we are now known as the Vancouver Acromegaly Support Group and became a Canada Not-for-profit with the Corporti0ns Act through the BC Government.

With each support group meeting it became clear that this was just the beginning of something wonderful for all of us. We could meet others, learn more and take care of ourselves better and understand our acromegaly better, and shared what help was available for all of us. To date there is now 50 members plus the partners and support people. We have become a family and help and support each other by being there when someone is going through hard times. We all bring our different knowledge together to help each other, from where to go for financial help, to understanding the different medications and the comfort of just knowing that no one is alone with Acromegaly.

As I started attending different conferences to learn more information to bring additional valuable information to the members and how this could help them, I was able to meet other acromegaly people throughout all the providences in Canada.

I was honored to be asked to attend the Halifax Acromegaly Support Group meeting for their 10-year anniversary. I was amazed by how many members attended and how welcomed they made me feel. To date they have been running for around 14 years and cover the Atlantic region of Canada.

As the years went by I had the wonderful opportunity to meet leading acromegaly endocrinologists throughout Canada and talking with them I realized that the statistics for acromegaly in Canada was quite higher than I thought. In Canada 4-6 people per million are diagnosed yearly and it is estimated that 60 per million have acromegaly, so there are just over 2,000 acromegaly patients. Just recently it was announced that it is believed that the stats are way off, and the leading acromegaly endos believe the numbers are 100's time per million and that they would not be surprised if this is incorrect and it is actually 1000's per million. People who have acromegaly are not getting diagnosed due to not enough knowledge known by the GP's in Canada. (I was shocked).

When we started the support group, I knew in my heart I was doing the right thing and I have never looked back. I was on a mission to bring acromegaly out of the wood work, for no one to feel alone and have people in Canada understand what acromegaly was throughout the public, so that when a loved one or family member or friend was diagnosed, they could talk to someone and have them understand what we were going through and what acromegaly was.

We are still working very hard on bringing more awareness out to the public, especially on Nov 1st, Acromegaly Awareness Day - and it is working. Acromegaly people are starting to spread the word by telling their personal stories, which I truly believe is the first step to acceptance to this disease and makes them confident that they can raise awareness also. So, I have implemented into our meetings that a member does a presentation on their journey, as we are all different and then with their permission put their story on our website for anyone to watch and learn.

Two years into our support group meeting I realized that we need to go National for Acromegaly in Canada and I had to try to make this happen, so we decided to take a leap of faith and host the First National/International Acromegaly Conference in Canada. My board and members agreed and we got started. For a year and a half, we were all on a huge learning curve, we needed to find a hotel that would work, bring in some serious funding to pay for everything, so we then decided to do a fundraiser for acromegaly. (This was amazing and met even more new members that brought more awareness out for acromegaly).

We invited the specialists who treated acromegaly people in to present, and we also wanted to have some acromegaly people present about their journey and why they became advocates for acromegaly in their own way and what they did. This brought the importance of being an advocate to the event, which could be done on many different levels. Small things had to be done, like agenda package, a hashtag sign, mugs & water bottles and bracelets supplied. These small items, even though some think irrelevant, actually worked to bring awareness and a subject point to talk about acromegaly.

On Sept 22nd-24th/2017 WE DID IT!!!!

We hosted the Acromegaly Conference, and what a huge great success.

On Friday Sept 22nd/2017 we released registration and a meet and greet with appies for 3 hours.

Saturday, 23 September 2017

The speakers that presented were:

Dr. Michelle Johnson - Endocrinologist: *How endocrinologists decide the right treatment for a patient.*

Dr. Angel Rigueras - Psychiatrist: *Pain management.*

Dr. Dan Holmes-Medical – Biochemist: *Lab process of testing our IGF-1 and GH blood work.*

Dr. Ryojo Akagami – Neurosurgeon: *Surgeries performed for acromegaly patients and what to watch for after surgery including the acromegaly Quality of Life Survey.*

Dr. Andrew Thamboo & Dr. Warren Mullings - Rhinology & Skull based surgeons: *Pituitary surgery from the Rhinological standpoint.*

Dr. Ehud Ur - Endocrinologist: *Upcoming trails for acromegaly patients in Canada.*

On Saturday night we hosted a BBQ Dinner for all those attending the conference including speakers and pharmaceutical representatives.

Sunday, 24 September 2017

The speakers presented where all acromegaly advocates:

Santino Matrondola: *His personal journey with acromegaly and the 2 pituitary surgeries and what he had done to bring awareness to the public in Montreal, Quebec.*

Dan Jefferies: *His personal journey with acromegaly and another rare disease and how he got involved with the UK Pituitary Foundation and hosted the first acromegaly support group meeting in the UK this year.*

J.D. Faccinetti: *Spoke on his personal journey with acromegaly and how he created a global website for Pituitary Disorders with Dr. Lewis Blevins called Pituitary World News.*

The conference was a huge success, I watched as everyone was glued to all the speakers and learning new knowledge. We noticed people coming to the conference not knowing anyone to leaving with new friends for life, to all of us crying through one presentation (as this was everyone's reality), and letting it out, to having us all laughing at the next presentation as it was presented in a way that had great humor. (Talk about great therapy for us all). Having the leading specialist also excited to be there to present and attend the first acromegaly conference was fantastic, and seeing pharmaceutical reps gaining new knowledge and truly understanding what it is like to have acromegaly was also great.

As I sit back now, (that's not true, there is so much more to do), I realized that I truly didn't have a clue on how to run a support group or put on an official conference, but I just knew it needed to be done, so we dove in and we made it happen. I am so glad we did, as this has all been a win/win for all people with acromegaly and the specialists. We will start getting better quality of care, but it also takes the patient to help take care of themselves better to help the specialist take care of us better - by closing the gap.

Do to the success of the conference we will be hosting another one in 2 years in another province in Canada, and with the Halifax Support Group and other support groups starting in other providences in Canada we are coming together and moving forward to become a National Acromegaly Organization in Canada.

I predict that within the next 2 years all of Canada will know what acromegaly is and that it does exist and those not diagnosed yet will be diagnosed and will live a better quality of life.

I am hoping to have the Ottawa Parliament in Canada next year recognize and approve Acromegaly Awareness Day Nationally for all of us. To date the BC Parliament has recognized and approved Nov 1st as Acromegaly Awareness Day in BC for the last two years and this helps me feel great to have this proclamation for all of us with Acromegaly.

If you are interested in view the pictures and video presentations, we have posted on our website to view.

Vancouver Acromegaly Support Group Website

<http://www.acromegalywest.com>

Twitter site: @AcroVan and @DeannaBadiuk16

Closed fb site for Acromegaly in Canada

Canadian National Acromegaly.



AWARENESS AND ACTION

By J D Faccinetti, Cofounder, President and CEO of Pituitary World News

We created Pituitary World News, a doctor-patient collaboration, with two basic ideas in mind: one, to work to try to reduce the time it takes for someone to get diagnosed properly. And two, to connect thought leaders with patients, and in doing so, provide a platform for collaboration that would result in creative, innovative ways of solving problems and improve Quality-of-Life through information and education.

Since our founding in September 2014, we've been listening to people's stories about their journey with diagnosis and treatments of pituitary disease. We have been attentively learning from the many voices of people affected by these tough diseases and the many related conditions they cause.

As patients, doctors, communicators, and publishers we work to understand the importance of our collective experiences in the quest to find solutions that are effective, sustainable and long-lasting. A big piece of the solution, we learned, is rather simple; listening to patients' voices will advance care and - most critically - aid in the development of new treatments. The good news is it seems these channels of communication and collaboration are taking shape.

Another critical, but no less important, component in any plan of action is awareness. Our awareness and action initiatives have been straightforward and can be divided into four main components:

- to provide patients useful information that improves knowledge of their disease and empowers patients to work more effectively with their physicians and healthcare professionals
- to create and develop tools so patients and patient outreach groups can be more effective advocates for their conditions
- to expand the PWN site's reach through communication, PR and public policy initiatives so more people are exposed to the content thereby increasing awareness of pituitary disease and recognition of signs and symptoms
- to collaborate with organizations from all over the world to make solutions more effective and long-lasting.

The case for awareness

The case for awareness is relatively simple. Awareness leads to interest, which leads to engagement, which leads to informed people and health professionals. A higher number of informed people (patients and healthcare professionals) undoubtedly leads to much lower numbers of misdiagnosed and undiagnosed, and importantly more people collaborating and working together to solve problems.

To date, increased awareness and collaboration efforts are helping diagnose thousands of people suffering around the globe. It is painfully evident that pituitary disease can go undiagnosed for decades and confused with a myriad of symptoms – like obesity, high blood pressure, diabetes, heart disease, weight gain, irritability, fatigue, colon polyps, sexual dysfunction, sleep apnea, headaches, visual loss, irregular periods in women, and many more. Physicians often treat the symptoms and don't explore the underlying causes delaying proper diagnosis for years. We aim to have patients better informed, and doctors put pituitary disease on their radars and consider it on the list of possibilities earlier in the process. But awareness alone does not solve problems. Awareness must be accompanied by action and careful consideration of the desired outcomes.

The strategies that improve awareness and action

One of the key elements of successful awareness efforts is to think about them strategically. In other words, developing comprehensive strategic communication roadmaps that produce programs with lasting effects. The literature on strategic communication to increase awareness point to three necessary elements that must be included in any plan:

- Plans should be designed collaboratively, preferably by multidisciplinary groups that include a variety of stakeholders with varied but complementary skills.
- They must be adapted to work locally for example through patient and other outreach support groups.
- They should be implemented on multiple levels. These levels are typically characterized by a multichannel integration of mass media, social media, two-way engagement and multiple stakeholders all working under a strategic blueprint with carefully designed evaluation methods.

There are many other specific considerations, tactical in nature, that are worth mentioning for their practical applications. These include:

- Integrated messaging and engagement of related conditions to pituitary diseases such as pain management, nutrition, exercise, arthritis, heart disease, weight gain, sleep apnea, diabetes, hypertension, and many more.
- Clear definition of target audiences. In a Pituitary World News brochure titled "[Increasing the Reach](#)"- [click here to download](#) - we assembled a comprehensive list of target audiences that have been identified for their ability to reach potential pituitary patients and caregivers and should be the focus for specific strategic messages. The initial messaging and engagement of key target and influencer audiences list includes:
 - Pituitary patients, families and loved ones
 - Related patient blogs
 - Primary care physicians
 - Related specialty physicians
 - Pharmacists
 - Ophthalmologists
 - Medical schools, nursing schools, and other health educators
 - Governmental organizations
 - Hospitals and clinics
 - Optometrists
 - Dentist and dental practitioners
 - Nurses and Nurse practitioners
 - Physical Therapists
 - Nutrition and weight management experts
 - Psychologists and behavioral professionals
 - General media outlets
 - Specialized health media channels
 - Online Public Relations distribution services
 - Trade organizations and professional directories
 - Professional trade journalists and bloggers
 - Key global and national media
 - Key health broadcast, print, and online programs
 - Special interest publications and blogs
 - Patient outreach/support groups

- Usage of mobile devices and other technologies that make it easier to track and recognize symptoms and signs.
- Usage of telehealth and other web-based educational platforms
- Smart usage of video programming and podcasts
- Involvement of local community through advocacy and support groups.
- A smart evidenced-based evaluation plan that will aid in future planning fine-tuning.

Some of the challenges: dealing with the “silent majority”

Analysis of our (PWN) audience and other available data leads me to believe that we, in the pituitary disease space, suffer from what some call “the silent majority” condition. Simply that means that the vast majority of people tend not to express their views, comment or engage in any way, even though they are highly interested in the content we offer. The concern is that it could be difficult to identify important opinions, which may be relevant to audiences and stakeholders alike. Conversely, those who engage and comment may not provide a balanced view of the needs of these patient communities. Engagement, therefore, is critical, and providing strong reasons to encourage participation and engagement in education and outreach activities is essential. Therefore, a critical planning step is to devise engagement programs that, whenever possible, seek opinions and comment from patients and organizations that may not typically choose to participate.

A word about long-term vision

Lastly, I'd like to make a few comments about the importance of a well-crafted organization's long-term vision (the brand), which is a crucial component of any strategic communication plan. An effective communication effort to increase awareness and action be it for a product, an idea, a concept, a cause, a condition, or a disease, requires the development of a robust well thought out long-term vision. The long-term vision is the brand, the soul, and the DNA of any program or endeavor - think of it as the glue that holds together all the parts of an awareness/action initiative.

Brands are about relationships formed by people's perceptions of communications and personal experience. To build a relationship an organization must first give its stakeholders and audiences a clear sense of who they are and what the organization stands for, clearly communicating that organization's core values and beliefs. The long-term vision (or brand) describes character and personality. It generates teamwork and commitment. It offers a set of emotional connections to stakeholders. It puts people at ease, builds trust in the information, and manages team members, stakeholders, and audience's expectations. This is critically important in areas, such as in pituitary disease, where people have so much anxiety as they deal with devastating changes in their lives and substantial quality of life issues.

Is it possible then to utilize Brand concepts to try to make those diseases better known and to encourage engagement? If we deliver accurate, useful information in a compelling way, generate conversations, and listen to the voices of all the stakeholders, the perceptions we create will generate more interest, engagement, change, and better outcomes.

We welcome our association with WAPO and other world-wide pituitary organizations dedicated to improving the lives of patients with pituitary diseases and look forward to many successful and effective collaborations.

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<https://www.pituitaryworldnews.org/>

WAPO CALENDAR OF EVENTS

If you have anything that you can add to the calendar that is happening in your country that we can add – please email ernest.lundu@wapo.org and we will include it. We would like your help to make sure we capture as many events and forums/conferences for our members from as many countries as possible.

The calendar includes:

- Events and conferences with sessions or content related to pituitary conditions (Global and local)
- Pituitary Related Awareness Days (Global and local)
- Other related awareness days (Global and local)

Where possible we have included links so you can find further information of how you can attend or be involved.

April 2018

April 8 – Global Cushing’s Awareness Day

April 11 to 14 – [Second International Congress of Kuwait Endocrine Society](#), KUWAIT

April 13 – [Contemporary Issues in Pituitary Disease 13th Annual Symposium](#), Weston, Florida USA

April 20 to 22 – WAPO Summit, Venice ITALY

April 28 to 29 – [Endocrine Summit](#), Mumbai, INDIA

May 2018

May 10 to 12 – [9th European Conference on Rare Diseases & Orphan Products](#), Vienna, AUSTRIA

May 19 to 22 – [20th European Congress of Endocrinology \(ECE 2018\)](#), Barcelona, SPAIN

June 2018

June 11 & 12 – [4th World Congress on Rare Diseases & Orphan Drugs](#), Dublin IRELAND

July 2018

July 15 to 18 – [9th International Congress of Neuroendocrinology](#), Toronto, Ontario, CANADA

July 23 to 24 – [Global Meeting on Diabetes & Endocrinology](#), Kuala Lumpur, MALAYSIA

August 2018

August 9 & 10 – [11th Edition of International Conference of Endocrinology](#), Madrid, SPAIN

August 29 & 30 – [5th Annual Conference on Rare Diseases & Orphan Drugs](#), Boston, Massachusetts, USA

September 2018

September 3 & 4 – [World Congress on Endocrinology & Metabolic Disorders](#), Auckland, NEW ZEALAND

September 13 to 16 – [2nd Biennial Rare Diseases Conference \(Rarex 2018\)](#), Johannesburg, SOUTH AFRICA

October 2018

Pituitary Awareness Month

October 1 & 2 - [12th Endocrinology, Diabetes & Metabolism Conference](#), Osaka, JAPAN

October 25 to 28 – [EndoBridge 2018](#), Antalya, TURKEY

November 2018

November 1 – Global Acromegaly Awareness Day

November 6 to 8 – [World Orphan Drug Congress](#), Barcelona, SPAIN

November 26 to 27 – [13th Endocrinology Congress](#), Dublin, IRELAND

FEATURE ARTICLE: PITUITARY SURGERY – POST-OPERATIVE FOLLOW UP

Dr. Lewis S. Blevins Jr is the Medical Director of the Center for Pituitary Disorders at the University of California, San Francisco, Professor of Clinical Medicine and Neurological Surgery and cofounder of Pituitary World News.

All too often, I see patients who come to the clinic with devastating recurrences of their pituitary tumors.



For example, the accompanying MRI depicts a recurrent pituitary tumor in a patient who had had surgery 10 years prior. He had one visit with the surgeon 6 weeks afterwards. No subsequent follow-up was rendered and he did not undergo any testing of the adequacy of pituitary functions. He recently presented with nasal congestion and other obstruction symptoms that were worsening over a four-month period. MRI shows a rather large and dramatic tumor emanating from the sella, invading the cavernous sinuses, and extending forwards occupying half of his nasal cavity, invading the ethmoid sinuses, etc. For all intents and purposes, this tumor is behaving as if it is malignant. There are two immediate lessons to be learned. First, you should undergo surgery at a pituitary centre of excellence with not only an experienced neurosurgeon but also a knowledgeable endocrinologist. Second, understand that lifelong follow-up is required. So, with this having been said, I would like to share with you some of my thoughts

about postoperative follow-up.

Follow-up 6-8 weeks after surgery is necessary to review the MRI to determine the extent of tumor resection, plan for any additional therapy for the tumor or any hormone excesses, evaluate the adequacy of pituitary functions, to allow for replacement hormones of pituitary function is compromised, and to establish a plan of long-term follow-up.

Studies show that between 12 and 18% of pituitary adenomas will recur. The majority of these recurrences take place within the first 3-5 years after surgery. Aggressive tumors recur sooner. The longest time from initial surgery to recurrence of a non-functioning tumor that I have encountered in my practice was 30 years. Patients with hormone secreting neoplasms usually recur sooner because the hormone perturbations lead to clinical attention in patients who have previously experienced acromegaly, Cushing's, or hyperprolactinemia.

The longest time from curative surgery to a documented recurrence I have seen in a patient with Cushing's disease was 15 years. Approximately 8-10% of patients who have Rathke's cleft cysts will develop a recurrent cyst. Those with infected Rathke's cleft cysts, or what are sometimes referred to as pituitary abscesses, face a 40-45% likelihood of recurrence unless they take postoperative antibiotics in which case the risk of recurrence is lowered closer to normal but is still higher than if the cyst is simple and uninfected. Patients with craniopharyngioma have a higher risk of recurrence that I would estimate to be 30-50%. Thus, lifelong follow-up is required and even when you think he might be rendered disease-free. I usually recommend MRI studies 6 weeks after surgery. I suggest a repeat study 6 months after surgery for those

who have residual tumors when there is a concern the tumor might be aggressive or likely to regrow quickly. I recommend MRI studies one year after surgery in patients whose initial postoperative MRI shows no evidence of residual disease. Thereafter, I recommend MRI studies on an annual basis for 3-5 years for most non-functioning pituitary tumors. Further, I suggest MRI studies whenever symptoms of the tumor, such as abnormal visual fields or headaches, recur in a pattern that was similar to the preoperative symptomatology. Obviously, I recommend repeat MRI studies when there is historical and physical as well as biochemical evidence of recurrent hormone hypersecretion in the setting of a history of a prolactinoma, acromegaly, Cushing's, and hyperthyroidism.

A number of patients have seemingly normal pituitary functions about 6-8 weeks after surgery. Interestingly, however, because of the way that hormones are bound to proteins, and possibly because the pituitary gland that is compromised by a tumor or surgery which might have interrupted its blood supply may slowly fail, reassessments of pituitary and target gland hormones to assess the adequacy of pituitary function are sometimes best performed at 12 to 16 or even 24 weeks after surgery, and especially in patients who have symptoms of hypopituitarism with an onset in this time frame after surgery. Those with partial or complete hypopituitarism or diabetes insipidus are followed on a regular basis according to individual needs.

Patients with prolactinomas who have been rendered disease-free after surgery should have prolactin levels at 6 month intervals for 2 years and then annually thereafter. The prolactin should also be reassessed in the presence of galactorrhea, irregular menses, infertility, or hypogonadism. Of course, those with residual disease or recurrent disease her on a totally different plan a follow-up that is tailored to individual needs based on any subsequent treatment and responses to such.

Patients with acromegaly who have been rendered disease-free after surgery should have IGF one and growth hormone levels obtained every 6 months for 5 years and then annually thereafter. Primary physicians often conduct these evaluations. Referral to the pituitary center should take place for any prolactin that exceeds 20 ng/mL and especially if there are symptoms of mass effect or gonadal dysfunction.

Patients with Cushing's syndrome who into remission usually have a period of adrenal insufficiency it lasts between 6 and 18 months. In one study, the average time patient's had adrenal insufficiency was 10.8 months. Steroid replacement is required until normal pituitary adrenal function is resumed. Follow-up should be individualized and is rather complex. Generally speaking, one of the main problems I see in this group of patients is that treating physicians administer supraphysiological doses of steroids which delay recovery. I prefer replacement doses of steroids immediately after surgery. I used dexamethasone 0.25-0.375 mg daily. If I choose to use a slightly supraphysiologic dose of steroids then I do so for no more than 6-12 weeks after surgery. Periodic morning cortisol levels are obtained after patients have withheld steroids for 24 hours. Once the serum cortisol level start to exceed 5-7 mcg/dL, I consider transitioning to a shorter acting steroid, such as hydrocortisone, for one to 2 months and then we'll perform a low dose ACTH stimulation test. If the stimulation test is normal the patient can come off steroids and we check a first, or baseline, 24-hour urine cortisol. If the response is abnormal, then we continue on low dose steroids until patients have a normal response based on testing in 2-3 month intervals. Once patients have discontinued steroids, I recommend 24 hour urine cortisols at six-month intervals for a couple of years and then annually thereafter. Also, the urine cortisol should be re-evaluated in the time patient believes hypercortisolism may have recurred. Additional studies, such as dexamethasone-suppressed CRH stimulation tests or salivary cortisol profiles may be

necessary to detect early recurrences as, in my experience, some patients recognize their Cushing's has recurred while their urine cortisol levels are still in the upper part of the normal range.

Patients who have been treated with radiotherapy to the pituitary region should undergo testing of pituitary functions at six-month intervals for a few years and then annually thereafter because 40-80% of them will develop one or more anterior pituitary hormone deficits.

PATIENT STORY: OLYMPIAN SCOTT HAMILTON FIGHTS RECURRING PITUITARY TUMOR WITH DIET AND EXERCISE

By Suzanne Potter

Olympic gold medal figure skater Scott Hamilton has always been a fighter. Over the past 21 years he's fought testicular cancer and three pituitary tumors. In fact, he's living with a recurrent craniopharyngioma right now – but has decided to put off surgery and pursue a different path: healthy living. And it appears to be working.

Hamilton's two most recent brain scans, in February and then December 2017, actually show that the tumor is shrinking. Hamilton, a devout Christian, calls it a divine miracle. "This doesn't really happen," he says, "I give all glory to God on this one. There are many talented people in the medical community but this is one they are having a hard time explaining."

Almost 40 years ago he lost his mother to cancer and has faced a string of life-threatening illnesses himself. In 1997 he beat testicular cancer. In 2004 Hamilton underwent radiation to battle the first appearance of his craniopharyngioma. It recurred six years later and he had gamma knife surgery in 2010. Then after another six years, it recurred again, in 2016.

When the tumor came back for a second time, he says he made a pact of sorts with God: he would do everything in his power to eat right and exercise and leave the rest to divine providence. Now, no one becomes a world-class athlete without enormous self-discipline and a fiercely competitive nature. So, Hamilton says he deployed that legendary determination to stick with a regimen that many a dieter has tried and failed: he cut out all sugar and all processed foods. Hamilton says, "I meant to try to figure out what I've done differently we go back to this: the definition of insanity is to do everything we always do and expect a different result. In my understanding of these cells, they love an acidic environment and they love sugar. So, I'm denying them both." Hamilton aims to starve the tumor by denying it sugar. And he drinks a lot of high-pH alkaline water, "to try to change the atmosphere surrounding the cells so anything bad doesn't really thrive." He also exercises regularly, to keep his body strong.

When asked if it was hard to eliminate sugar and processed foods, Hamilton replied, "It's hard but that's where faith comes in. If I make a pact to say I'm going to do this and be obedient I feel like I'm doing the best that I can. If I am able to avoid surgery for as long as possible that is the goal."



In 2008, Hamilton received the PNA's highest honor, the Gentle Giant Award, from founder Bob Knutzen for the Olympian's work promoting pituitary awareness.

Hamilton has a lot to live for: his wife Tracie and four kids, ages 10 to 16. Not to mention a long career in sports broadcasting (he just got back from a month in Seoul as part of the NBC Sports team covering the Olympics). His [Scott Hamilton CARES Foundation](#) raises money for cancer research and has funded a chair at Vanderbilt University, funding scientists who study the effects of chemotherapy on children. Hamilton says chemo and radiation have too many long-term side effects: “There are ways to endure it but why make the whole body suffer when we are just trying to evict the cancer.”

He also supports research into targeted immunotherapy and aims for a better understanding of the potential of proton therapy, something noted pituitary neurosurgeon Dr. Ed Laws at Brigham and Women’s Hospital in Boston calls an “elegant solution” for many tumors. The CARES Foundation [SK8 to ELIMIN8 campaign](#) does peer-to-peer fundraising with skaters and their families reaching out to their friends and loved ones to raise money for more research. He has been involved with the Special Olympics for many years and has been a longtime supporter of the Pituitary Network Association, raising awareness of pituitary disorders.

Hamilton’s doctors have advised him that he is not a good candidate for proton therapy because he had gamma knife in the past. His only choice later on may be to have surgery again, but he says he’s opting to change his diet and see where that takes him.

Hamilton is also a motivational speaker and has recently published his third book, called *Finish First: Winning Changes Everything*. In the book, he shows people how to harness the competitive spirit to accomplish their goals, be they in business, academics, or elsewhere. He adds, “The main thing is to look at who we are as people, what we want to accomplish. Figure out the reasons why we want to do that and know that there is a path forward.”



He also advises people to reframe any setbacks as information that helps us get where we need to be heading. He says he fell thousands of times as a skater and got back up every single time. “People are afraid of failure,” he says, “This pursuit of perfection, where you’d rather not fail. I try to reidentify failure as an incredible opportunity to grow.”

In 1984 that attitude led him to a gold medal. Now he’s facing his latest life challenge with extreme action on a personal level with diet and exercise, and by funding research that may help him and millions of others down the line. “As long as I’m participating in research, tumors like mine may develop new treatments either by design or by accident.”

He realizes that his approach to fighting the pituitary tumor with diet and exercise is a gamble. “It’s either really smart on my behalf, or really stupid, the jury is out.” Hamilton says he’s focused on his family and his life purpose: to inspire others to be their best selves and push for new treatments in the battle against cancer.

We encourage you to ask a clinician in your country to write an article of interest for the newsletter. And for you to spread the love yourself by contributing your story of your journey.

Please send to Sue Kozij – Sue.Kozij@wapo.org

2018 WAPO SUMMIT UPDATE

In a week, the 3rd WAPO Summit 2018 edition will happen!

At this moment we have 36 patient advocacies registered and will have the speakers and industry representatives joining the program from April 20 – 22, 2018.

This year we will introduce the 'Guidebook app' in order to save paperwork and printing. All attendants would have received a link incl. the program, travel and hotel information, etc.

We are really looking forward to meeting again with patient advocates, speakers and industry representatives. Together we will make the Summit a success!

If you can't join us this year, we'd like to invite you for the next WAPO Summit ... 😊

If you would like to respond to the above, please mail: mail@wapo.org

WAPO SUMMIT 2018 - AGENDA

WAPO Summit 2018
'Living a positive and healthy life'
AGENDA
20-22 April, 2018 – Quarto d'Altino, Italy



Friday April 20, 2018

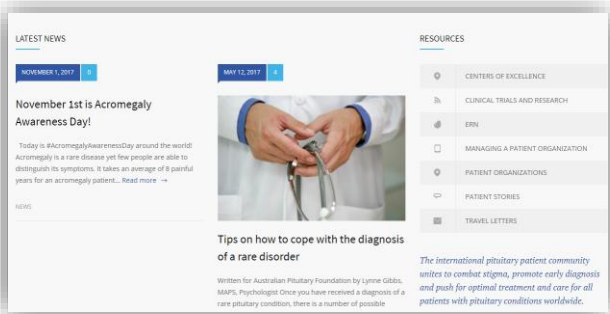
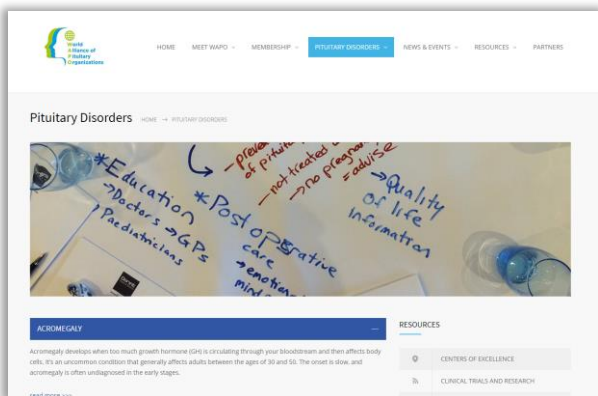
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|---------------|---|
| 15.00 | Welcome incl. WAPO update and summit overview incl. introduction all participants |
| 15.15 | Brief Twitter and Social Media Wall introduction
by Fabio Neri - Mesa-Lab, Italy |
| 15.40 | Sharing of Best Practices
by Patient Advocates |
| 17.30 | End of Day Program |
| 17:30 - 18:30 | Meeting Pharma Industry - WAPO Board
(meeting for pharma representatives and WAPO Board of Directors) |
| 19:00 | Welcome dinner (All) |

Saturday April 21, 2018

- 8:30 **Introduction and welcome by program director Kathy Redmond**
- 8:35 **Optimizing pituitary hormone replacement incl. Q&A**
by Professor Richard Ross - University Sheffield (UK)
- 9:30 **Pituitary Centres of Reference incl Q&A**
by Professor Felipe Casanueva - University Santiago de Compostela
- 10:15 Coffee
- 10:45 **Importance of the multidisciplinary team (pituitary unit) incl. Q&A**
by Professor Federico Gatto - University Genova (Italy)
- 11:30 **Advocating for access to centers of excellence in Pituitary care**
(dialogue between all speakers and patient advocates)
- 12:15 Lunch
- 13:30 **Increasing our impact in**
- raising awareness about pituitary conditions (Andrei)
- advocating for access to approved pituitary therapies (Sue)
- improving sustainability of pituitary organizations (general discussion)
- 15:30 Coffee
- 15:45 **Introduction to Mindfulness**
by Dr. Michelle Zandvoort - The Professional Psychology Practice (UK)
- 17:30 **Conclusion, picture and close Day 2**
- 17:55 **Dinner** (*outdoor - bus will leave at 18:00*)

Sunday April 22, 2018

- 08:30-9:15 **Sponsors de-brief meeting** between industry representatives and
WAPO Board of Directors
- Chair and moderator: Kathy Redmond**
- 09:30 **Announcement of Poster Winners**
by Sheila Khawaja
- 09:45 **WAPO AGM 2018** (WAPO Members only)
- 11:00 Break
- 12:45 **Farewell & celebration lunch** (All)
- 13:30 - 16:00 **WAPO Board of Directors Meeting** (incl. elected new directors)



Screenshots from the WAPO Website 9 March 2018

– www.wapo.org

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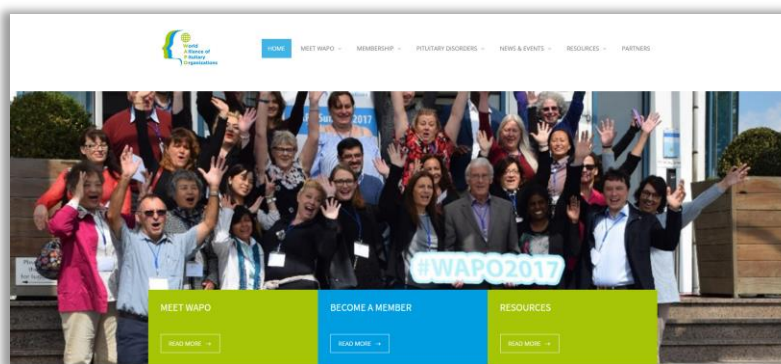
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WEBSITE

www.wapo.org Please keep checking the WAPO website.



DISCLAIMER

The information in this Newsletter, whether provided by WAPO or any third party, is not intended to be used as a substitute for professional health or other advice. The content of patient’s stories are the opinion of individuals and not the World Alliance of Pituitary Organizations or its office bearers.

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