

# THE GLOBAL PITUITARY VOICE

JOURNAL FROM WAPO

EDITION 5 | DECEMBER 2017



## 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

So many things happened in the pituitary advocacy world since our last edition!



I will start with sad news. Arnold Forter, the president of 'Wegweiser', the Swiss member of WAPO, passed away on October 25, 2017 after being diagnosed with cancer in the summer after the WAPO Summit. Arnold took part in several meetings we had and contributed to our common activities. We will certainly remember him as an open and kind person and a very active patient advocate!

On the 1st of November we had the Acromegaly awareness day. Several organizations including WAPO launched awareness campaigns with the [#AcromegalyAwarenessDay](#) hashtag. Altogether only on Twitter and Instagram more than 170 posts were made in at least 15 countries. The posts reached more than 65 000 people. It is the most massive acromegaly awareness campaign we have ever seen. To be fully satisfied with these results, we look forward to hearing stories of patients that were diagnosed as a result of the campaign.

October is the pituitary awareness month. This October we have seen activity in the UK, the campaign was [focused on opticians](#) as one of the most frequent doctors to spot the pituitary issues. We are planning the pituitary awareness months of 2018 and, even earlier, the Cushing's awareness day on the 8th of April. We will be happy to hear your ideas and have you in the Global Awareness team!

Sheila Khawaja and Muriël Marks have represented WAPO during the World Orphan Drug Congress in Barcelona (November 13-15, 2017). They met with interesting organizations and share this in an article. If you like to see more pictures, please have a look at our album on Facebook - <https://www.facebook.com/wapo.org>.

During the last months, we've started a dialogue with important global partners, like PFMD ([Patient Focused Medicines Development](#)), [Global Genes](#) and [FindMeCure](#). We will introduce the Rare Bear Project in the next Newsletter in March 2018. Also, the [World Pituitary News](#) will work together with WAPO to improve information to our members. JD Faccinetti (CEO) will join us at the WAPO Summit 2018.

Of course we'd like to welcome 'Pituitary World News' and JD Faccinetti (founder) who have recently become a WAPO member! 'Pituitary World News' (PWN) is a publication and a publishing platform dedicated to help diagnose people properly and early by increasing awareness of pituitary disorders and providing a platform for communications, collaborations, creativity and innovation. PWN wants their partners and collaborators to share their story and expertise, and be part of this movement to change how we spread knowledge and information.

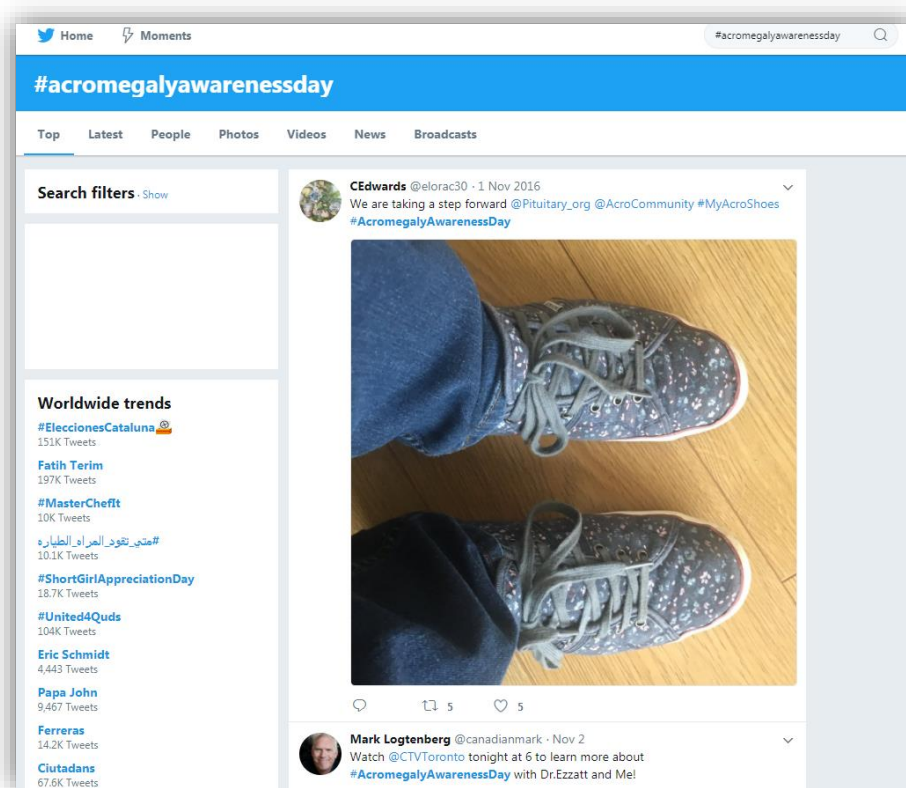
Furthermore, the WAPO Summit 2018 program is final with interesting speakers. Subjects like Mindfulness, Hormone replacement, Centers of Excellence and Multidisciplinary teams will be presented upon. If you are a pituitary patient organization and you would like to represent your organization during the Summit 2018, please contact WAPO through [muriel.marks@wapo.org](mailto:muriel.marks@wapo.org)

And last but not least ... if you have information on pituitary related activities or congresses, please share them at [mail@wapo.org](mailto:mail@wapo.org) and we'll share them in our Calendar!

More news from the pituitary patient world, patient stories and a featured article in this (5th) issue of The Global Pituitary Voice.

Have a nice reading of the 5<sup>th</sup> edition of the Global Pituitary Voice. I wish you a Merry Christmas and Happy New Year.

Andrei Andrusov: WAPO Board Chair



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## 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.

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## UNITED STATES OF AMERICA

The third week of September, The MAGIC Foundation celebrated "Growth Awareness Week". In 2017 this was our most successful awareness campaign ever accomplished. Organizations from around the world participated in this event bringing about the importance of growth in children. In 2014 MAGIC was awarded with a Congressional Resolution for "Growth Awareness Week" to be initiated each third week of September annually.

MAGIC is in the final stages of coordinating our 2018 Annual Educational Convention, to be held in Lombard, Illinois on July 12-15, 2018. Families from a multitude of growth disorders will attend with over 30 medical professional speakers and social activities for all. Our 2018 Convention program will be on MAGIC's web site in January, 2018. [www.magicfoundation.org](http://www.magicfoundation.org). An estimated 1,000 attendees will be able to learn more about their child's growth disorder, updates in the field of endocrinology and have the opportunity to network with many other families.

In January, 2018, Team MAGIC will participate in the Disney Marathon held at Walt Disney World, Orlando, Florida. Runners from around the country join team MAGIC to raise money for support of children with growth disorders.

Happy Holidays to one and all from MAGIC!

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Relative to the patient group there is a lot of information. On December 3<sup>rd</sup> and 4<sup>th</sup> we presented two workshops: one referring to the pituitary and the health problems for people with acromegaly, and one on general topics of problems with growth hormone. There also was a quarter topic on the rights of patients.

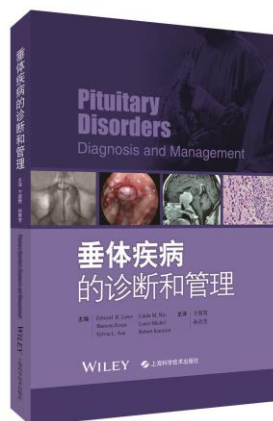
These workshops were presented in the Department of Petén, a place 800 kilometers from Guatemala City. Outreach information was shared on social networks. We will provide more information in the next newsletter.



## UNITED STATES OF AMERICA

The PNA is very pleased to announce that our book, Pituitary Disorders: Diagnosis and Management is now being published in China. Co-author Dr. Shereen Ezzat recently traveled to Beijing to represent the PNA on the occasion of the official book launch in China. The other co-authors are Dr. Edward Laws, Dr. Sylvia Asa, PNA co-founder Robert Knutzen, Lorin Michaels and Linda Rio.

This book has now truly circled the globe and is an achievement that everyone at PNA is very proud of!





UNITED KINGDOM

We have been very busy within The Pituitary Foundation, raising awareness of conditions within our policy and campaigns work and extending our patient services.

For our summer campaign The Pituitary Foundation worked with University Hospitals Bristol NHS Foundation Trust, to encourage all hospitals to have a protocol in place for managing patients with adrenal insufficiency.

University Hospitals Bristol NHS Foundation Trust made their protocol available for other hospitals to adopt, or to use it as a template.

For Pituitary Awareness Month in October this year we used our campaign to boost optician awareness of pituitary conditions - building on the very successful campaign from autumn 2016. We also provided input to The Global Awareness Team, particularly focusing on Acromegaly Awareness Day on 1<sup>st</sup> November.



Our involvement with NHS England Clinical Reference Group continues, and we have registered as stakeholders to provide comments towards updating Quality Standards (QS) to the National Institute for Health and Care Excellence (NICE). Comments towards updated Quality Standards have already been submitted for Depression in Adults - Recognition and Management, and we will be submitting comments for two other areas of medicine- Emergency and Acute Medical Care QS, Chronic Fatigue QS and Depression in Adults with Chronic Physical Health Problems- recognition and management

We were delighted to have a stand at the British Endocrine Society's National Conference again this year, and in addition Sammy Harbut was invited to speak about her patient journey. This was well received by Endocrinologists, Specialist Endocrine nurses and Pharmaceutical Company Reps alike. Sammy has also continued to visit many of our Local Support Groups throughout the UK this year, providing advice and information about fatigue management.

On 25<sup>th</sup> November 2017 we are holding our National Conference in Birmingham. We have 200 delegates registered, and are expecting the event to be successful as in other years. We have specialist speakers from Birmingham University Foundation Trust Hospitals, including Dr. Niki Karavitaki (Consultant Endocrinologist), Sherwin Criseno & Andrea Mason (Specialist Endocrine Nurses), and Mr. Alessandro Paluzzi (Consultant Neurosurgeon). Afternoon workshops include Adrenal Insufficiency & steroid regimes, Paediatric and transition Endocrinology, Diabetes Insipidus, Living with Hypopituitarism, and a session for Carers & families.



This year we are also hosting a Social Evening for delegates following the Conference, and again there has been much interest in this.

This year has seen us introduce patient ‘webinars’, and we have held discussions about fatigue management, adrenal insufficiency and sick day rules, Cushing’s and Acromegaly. We also provided a volunteer training event in April, which provided our volunteers an opportunity to catch up with each other, receive information about Data Protection issues and how to provide the best service possible, whatever their volunteering capacity. The feedback from all who attended was very positive, and as an organization we were able to celebrate and thank them for their passion, dedication and skills.

Our Senior Fundraising Manager has organized some incredible events this year. Some of our amazing supporters have taken part in various challenges including three sponsored mountain climbs, a zipwire challenge, abseil from the Orbit structure (below), autumn stampede, Cycle rides, Marathons and half marathons.





**UNITED STATES OF AMERICA**

In honor of November 1st being awareness day for acromegaly, Acromegaly Community would like to extend the invitation of sending out awareness bracelets to other acromegaly groups around the world. If you send us your information we will send you out a couple hundred bracelets and information on how to order more if you would like. Our members seem to like the bracelets because they are thinner than the typical awareness bracelet. And it states simply — ACROMEGALY Diagnose & Cure. It has no branding on it, it is simply for awareness. If you would like me to send you some to distribute, please send me your name and address. My email is [acromegalyinspiration@gmail.com](mailto:acromegalyinspiration@gmail.com) Together we are strong, please do your part to help spread awareness.



[China](#)  
[Acromegaly](#)  
[Patient](#)  
[Association](#)



**PEOPLES REPUBLIC OF CHINA - PRC**

CAPA participated in the WAPO summit in 2017, and feels very much the sunshine and positive results of the summit board members and patients in various regions of the world.

This kind of learning communication has a positive effect on CAPA's work.

Talk to everyone about CAPA's recent work!

1. Invite 9 patients of pituitary adenoma group joined: for common knowledge about diseases, resource sharing, CAPA has invited limb patients group of Zhejiang, Hebei nine patients of pituitary adenoma of organizations such as medicine, west China join CAPA and try to run for a period of time.
2. Lecture arrangement: Because of the different national conditions, our patients may need to know more about diseases related knowledge and do their own health management. So CAPA has arranged a series of lectures on pituitary tumors that have continued in the public interest network since September 2013, which has been completed since September 2013.

THE VALUE OF SSA IN PREOPERATIVE TREATMENT	Dr. Qingfang Sun Shanghai Ruijin Hospital Neurosurgery
THE IMPORTANCE OF HORMONE DETECTION AND FOLLOW-UP IN ACROMEGALY PATIENTS	Dr. Chaoyun Zhang Shanghai Huashan Hospital Endocrinology Department

Number for pituitary tumor experts lecturers : Zimeng Jin, YuQi, Lin-Jie Wang, Gu Feng, Li Yiming, Hongying Ye, Chaoyun Zhang, Bowen Cai, Wei Yan. They are from Peking Union Medical College, Shanghai Huashan, Chengdu Huaxi and Zhejiang second hospital, etc.



According to incomplete statistics, as of October 8, we had views of more than 5000 people; there were 20 doctors, including endocrinology in Guangdong Zhongshan Hospital - Doctor Zhihong Liao, she was viewed more than 8000 times.



Photo of the lecturer presented by CAPA



### 3. Try to speak at the doctor's academic conference

To convey to more doctors in patients with acromegaly some of the ideas and medical situation, establish a good interaction between patients, 2017 in Nanjing PURPLE MOUNTAIN ENDOSCOPIC NEUROSURGERY & PITUITARY SUMMIT we strive for a chance to speak to a conference.

So, we used 2015 data from the baseline survey of CAPA to reflect the urgent problems before and after the operation of patients with acromegaly, such as headache, which accounted for 54.3 percent.

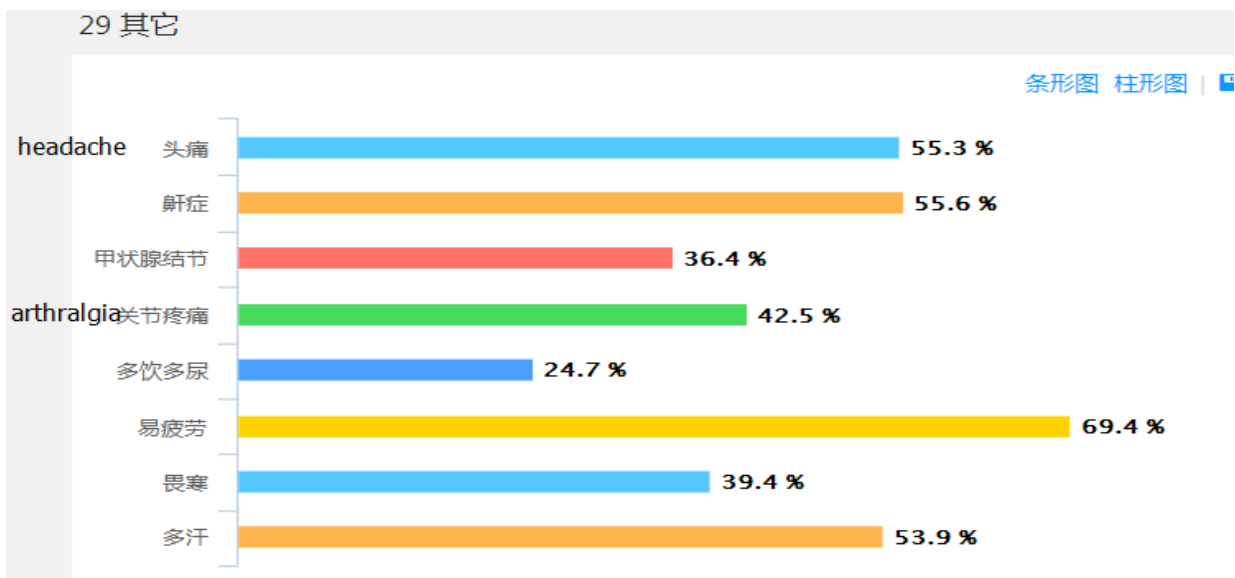
Women's menstrual problems accounted for 86%;

The values of GH and IGF1 are discrete and so on.

Some doctors took pictures and asked for PPT to continue to understand and explore.

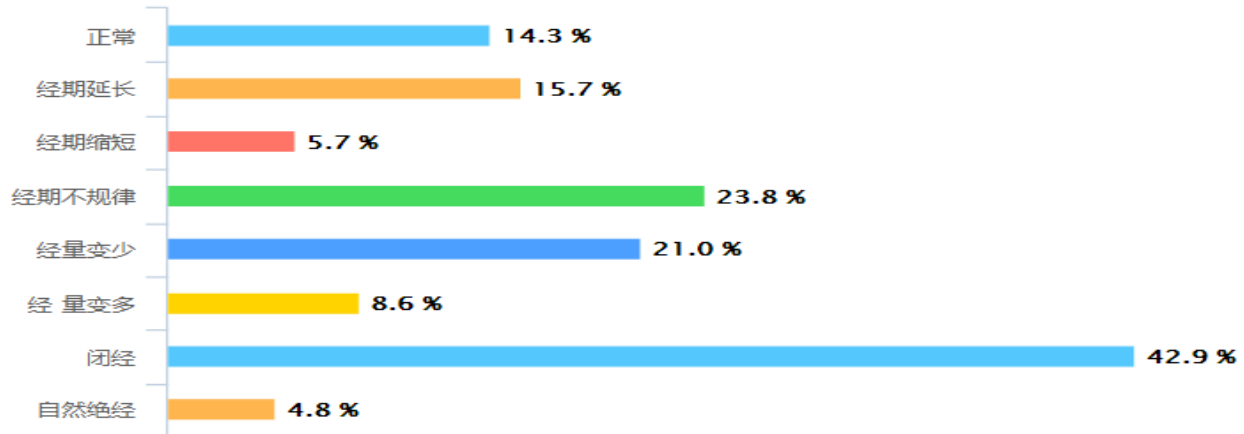
We call on the outside doctors to focus on these issues and to **Haining Wei speaking** increase the rate of early diagnosis;

It is hoped that the nationwide investigation of limb pandemic will be carried out as soon as possible.



## 30 月经情况 (女性填写)

条形图 柱形图 | 



### A screenshot of the baseline survey

#### 4. Baseline survey

For limb large medicine into the medical security, to promote medical research and drug development to strengthen the construction of CAPA organization and CAPA in February to the end of this year the end of the patients with baseline survey has completed 375 times so far.

Introduction to registration:

1. Basic situation of patients: 1-16;
- li. Diagnosis and treatment: 17-48;
- lii. Medical expenses: problem 49;
- Iv. Psychological intervention: 50-60 questions.

5. Participated in WAPO to launch global limb awareness day, and the WeChat micro blog of CAPA was also reproduced on the first day of the activity.



## 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](mailto: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.

### January 2018

January 20 to 23 – [54<sup>th</sup> Annual Clinical Diabetes & Endocrinology Conference](#), Colorado USA

### February 2018

February 1 – 20<sup>th</sup> [Clinicopathological Conference on Pituitary Disease](#), Royal College of Obstetricians and Gynaecologists, London UK NW1 4RG

February 2 – [Pituitary, Thyroid and Parathyroid Update 2018](#), Portland, Oregon USA

February 28 – [Rare Diseases Day](#)

### March 2018

March 1 to 3 – [Emirates Diabetes and Endocrine Congress](#), Dubai UAE

March 7 to 9 – [Orphan Drugs and Rare Diseases Global Congress](#), London UK

March 17 to 20 – [Endo2018](#), Chicago USA

March 23 to 25 – [Conference on Adrenal Insufficiency](#), Kansas City, Missouri USA

### April 2018

April 8 – Global Cushing's Awareness Day

April 20 to 22 – WAPO Summit, Venice ITALY

### May 2018

### June 2018

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



## 2018 WAPO SUMMIT

The program is final and speakers have confirmed their attendance!!! We herewith present our program for the Summit 2018! The Summit will be held in the surroundings of Venice, Italy from April 20 – 22, 2018.

We would like to meet with new pituitary patient organizations and invite you to join the WAPO Summit 2018 as a patient advocate on behalf of the board of your organization!

If you are interested and need more details or would like to sponsor the Summit, please contact:

[muriel.marks@wapo.org](mailto:muriel.marks@wapo.org)

## WAPO Summit 2018 *'Living a positive and healthy life'*



### AGENDA

20-22 April, 2018 – Venice, Italy

#### April 20, 2018

- 15:00 **Welcome incl. WAPO update and summit overview incl. introduction all participants**
- 15:10 **Brief Twitter and Social Media Wall introduction**  
by Mesa-Lab, Italy
- 15:30 **Sharing of Advocacy Projects of your organization**  
by Patient Advocates
- 17:00 **End of Day Program**
- 18:30 **Welcome dinner**

#### April 21, 2018

- 8:30 **Introduction and welcome by program director Kathy Redmond**
- 8:35 **Optimizing pituitary hormone replacement incl. Q&A**  
by Prof. Richard Ross (UK)
- 9:30 **Pituitary Centers of Reference incl. Q&A**  
by Dr. Felipe Casanueva (Spain)
- 10:15 **Coffee**

- 10:45 **Importance of the multidisciplinary team (pituitary unit) incl. Q&A**  
by Dr. Diego Ferone (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 **Introduction to Mindfulness**  
by Dr. Michelle Zandvoort (UK)
- 15:15 Coffee
- 15:30 **'World Café' session: Developing a plan of action on**  
  - raising awareness about pituitary conditions
  - advocating to access to Pituitary Reference Centers
  - promoting QoL for people living with pituitary conditions
  - advocating for access to innovative therapy
  - improving sustainability of pituitary organizations
- 17:30 Conclusion and close Day 2 (incl. pictures)
- 18:15 **Dinner (outdoor)**

#### April 22, 2018

- 08:00-9:00 **Sponsors de-brief meeting** between industry sponsors and  
WAPO Board and WAPO Board of Directors  
Note: only for sponsors and WAPO Board

#### 2018 Annual General Meeting

- Chair and moderator: Kathy Redmond and Andrei Andrusov
- 09:15 **Review 2017/2018 and future vision WAPO**  
incl. Best Poster election
- 11:00 **Short break**
- 11:30 **WAPO's inaugural meeting (WAPO members only)**  
  - Election of Board Members (Board of Directors)
  - Minutes WAPO AGM 2017
  - WAPO activities for 2018/2019
  - Any other business
- 12:45 **Farewell Ceremony and Celebration lunch**

## FEATURE ARTICLE: WHY CAN CORTISOL MAKE US OBESE?

Professor Onno C. Meijer, Leiden University Medical Center, The Netherlands

Cushing's Syndrome is what happens when we are exposed to (way) too much cortisol, or its synthetic variants. Out of the many unwanted aspects of Cushing's, fat accumulation is the most visible one, and also one of the biggest risks for additional health problems. The medical jargon talks – perhaps rather callously - about 'truncal obesity', 'moon face', and 'buffalo hump'. The latter refers to the accumulation of fat in between the shoulders. This is such a typical feature of cortisol access that, when scientists were able to generate an animal model for Cushing's Disease, they prominently displayed a picture of this mouse-with-buffalo hump in the article that described their work. Why does cortisol lead to the appearance of all this fat?

The answer is related to the normal role of cortisol as a stress hormone. When we encounter a stressful situation, we need to somehow cope with that situation – we get 'stressed'. Being stressed means being in a particular 'state', not only mentally, but also physically. Although stress has a bad reputation, the stress response is essential for survival, as all organisms will meet challenges in their lives that require this state of being stressed.

The body has very effective ways of bringing about physical states: hormones. Hormones are messenger molecules that come from one source ('glands' such as the adrenal gland). The power of hormones lies in the fact that they are transported via the blood to reach each and every cell in the body. They are 'public announcements', and as such a perfect way to bring about a coordinated change in the activity of many organs. They can cause a different state.

*Immediately* at the start of the stress response, the hormone adrenalin (a.k.a. epinephrine) is released to support the 'fight or flight' response. In other words: adrenalin prepares the body for active coping with the stressful situation. Adrenalin for example 'tells' the liver to release sugar and fat into the blood, which can be burned by muscles, to actually make us able to fight or flight. But this effect of adrenalin is relatively short lasting. Enter: cortisol. Cortisol is our second major stress hormone, slower, but ever so powerful. Its levels in the blood typically will start to increase after a couple of minutes. Cortisol levels can remain elevated for days or weeks when stress is chronic. One of the functions of cortisol is to support a *sustained* stress response.

Cortisol acts slower than adrenalin but in a more profound manner. Like adrenalin, cortisol tells the liver to spit out its stored sugar and fat as food for muscles, but it also tells the liver to make *new* sugar and fat. While both hormones tell the liver to make energy available, cortisol is the one to replenish the liver energy stores. What happens under the influence of cortisol is that the liver actually uses all the resources it can find and converts these into sugar and fat for the other organs to use. In parallel cortisol causes breakdown of muscles that are not being used, in order to generate building blocks for fat and sugar production in the liver<sup>1</sup>. Effective coordination by cortisol...<sup>2</sup>

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<sup>1</sup> This breaking down of muscles is called a '*catabolic*' action. Androgens, the male sex hormones, do the opposite and support muscle growth – these are then the *anabolic* steroids.

<sup>2</sup> One of the other organs that is part of this same coordination is the brain, that starts to generate hunger signals under the influence of cortisol. Although in case of acute threats this effect is counteracted by other stress factors in the brain. This is why stressed people may either eat more *or* less than normally.

These cortisol effects can be really useful for different stress-situations. For actual fight-flight we need the sugar and fat. If the stressor would be starvation, it is even useful to break down muscles to ensure activity of the vital organs. However, in case of Cushing's syndrome, the patient is normally at rest and does not *need* all this extra energy. Yet: it is there in the blood. What happens next?

The body cannot do many things with sugar and fat circulating in the blood. In fact: with fat it can do only do two things. It can burn it (normally into calories, that is: fuel for our muscles and other organs). Or it can store it: in our fat depots. With sugar there is one more option: the body can turn it into fat. To burn, or to store. And so: what cortisol does here, is to ensure that more than plenty of fat is present in the blood, even by breaking down muscles. That fat has nowhere to go other than into its depots: and here we arrive at obesity. And, for that matter, at thinning of arms and legs, as muscles are actively being told to shrink and return their building blocks to generate 'fuel'. A nasty consequence of what normally is a healthy response to adapt to stressors.

What we do not know, is why fat accumulates in the face and in between the shoulders. It may be that the latter involves a sort of reactivation of a special fat organ: the brown fat (also known as Brown Adipose Tissue, or BAT). This is a special type of tissue that takes up fat, but does not store it. BAT rather burns fat into heat. BAT is present in large amounts in babies: they have a relatively large surface and therefore loose heat more than adults. The major location of BAT in babies is right in between the shoulders. The bad thing is that the buffalo hump may represent 'awakened' BAT tissue, but that this BAT tissue only stores the fat and does not burn it (otherwise there would be no accumulation)<sup>3</sup>.

And so, the unpleasant effect of cortisol on fat accumulation does make sense. The increase in glucose in parallel increases the risk to develop diabetes. The friend that cortisol normally is, turns into a foe: it is really too much of a good thing.

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<sup>3</sup> Adults *do* have some active brown fat tissue, located more inside the body. Activating this BAT is presently a popular subject in research on obesity. Activated BAT will simply take up fat from the blood and make it disappear as heat (and some CO<sub>2</sub> and water). A sure (but limited) way to lose calories.

## PATIENT STORY: ERELLA

In 1998, a single parent with a child starting Kindergarten, I noticed some unusual symptoms. I had a high stress job as a multimedia designer after decades as a music journalist. Every doctor and specialist I managed to get time off work to see ascribed it as an issue with stress.

Eventually, I saw an endocrinologist who told me I had a “mass at the base of my hypothalamus”, then he promptly left the room to take a call. After a long wait, I was ushered to the crowded waiting area because the specialist had forgotten about me. There, in front of a room full of strangers, I learned I had the first of three brain tumours.

It took 15 months of testing to confirm the diagnosis of Cushing's Disease due to the large tumour on my pituitary gland.

I showed the MRI and CT scans to three neurosurgeons who all agreed that the tumour, the size of a golf-ball, had to be removed as soon as possible. It was astonishing however, that the three of neurosurgeons viewed the same test results and had substantially different routes to get at the tumour with significantly different recovery times and risks.

The head of neurosurgery advised that Transcranial surgery was the only option.

The second surgeon wanted to get the tumour through the roof of my mouth.

A leading neurosurgeon, accepted my case. He performed the first two transphenoidal surgeries. He commented that my first macro adenoma was “big tumour, little Cushing’s” and the second was “big Cushing's, smaller tumour”!

Recovery from these surgeries took a surprisingly long period of time. Luckily, I had a community of artists that looked after me and my daughter. This period of my life was captured by CBC National Radio and became an award-winning documentary:

<https://soundcloud.com/erella-beaubella/cbc-radio-ideas-erella-ganon>

In spring of 2008, a third tumour was discovered. It was either sitting on top of or growing on the carotid artery and surgery would be super risky. I was informed that if the tumour wasn't removed I would not live to see Christmas that year. The surgeons' I spoke to declined to take this on.

At this same time, urgent repairs and maintenance was needed on my house; the year was particularly snowy and weather dipped to below 25C. The plumbing seized then the roof caved in. Friends got involved relocating treasures, selling items, figuring out contractors and eventually making my home safe again. Local restaurants sent over food, my sister would drop over regularly offering help. My daughter was trying to keep a normal life, attending high school during the day and working on the house and looking after me during the night. I was very grateful for the wonderful support and care I received.

[https://www.thestar.com/life/health\\_wellness/2008/05/20/in\\_the\\_performance\\_of\\_a\\_lifeline.html](https://www.thestar.com/life/health_wellness/2008/05/20/in_the_performance_of_a_lifeline.html)



Making decisions and finding alternative solutions for accommodation was extremely stressful on top of the added medical issues. Locating a surgeon that would take on this very risky surgery was much more urgent. My cortisol levels were soaring and I was trying all sorts of alternative and odd remedies to lower the cortisol levels so that I could make some decisions. I took Ketoconizol, (a fungal remedy) but when taken in high doses, can lower a person's cortisol levels. Problem was that I couldn't stand the drug or the side effect; the vomiting and cramps were dreadful. I constantly felt as though someone was scraping my insides with a knife.

Finally, a neurosurgeon was coerced and agreed to do the surgery. He got as close to the carotid artery as he safely could to remove the mass. About six months later I had radiation therapy to remove a bit more of the tumour. During this therapy, I had a gall bladder attack. Radiation therapy was halted and my gall bladder surgically removed. This too was risky because lacerations take a long time to heal when a patient is undergoing radiation. The second round of radiation therapy took much longer to recover from.

I continued having two MRIs each year. In 2011 another pituitary tumour was located and Cushing's symptoms become more pronounced. I had a bilateral adrenalectomy to remove both of my adrenal glands that were feeding my tumour.

Recovering from that and learning how to live without adrenals has been a long learning curve.

In February 2017, I had knee replacement surgery. At pre-admission, I was informed not to bring any medications from home. The surgery went well even though I am anaphylactic and super allergic to most pain meds from Morphine, Oxycodone, Hydromorphone to Advil.

Post-surgery, I was transferred to a rehabilitation hospital. While there, I had an Adrenal Crisis. Alas, the rehab hospital did not stock Solu-cortef. I needed my emergency kit OR I WOULD DIE. An ambulance was ordered to transport me to an acute care hospital. Fortunately, my daughter was visiting at the time and strongly advocated for the urgent administration of 100ml Solu-cortef IV. The paramedic's response was they don't carry the necessary life-saving medication and didn't think this unusual medicine would be available at the hospital emergency room in time. My daughter had no choice but to return home, pick-up my medication and meet us at the other hospital.

By this time, I was unable to speak. They put me on a gurney in the garage area of the ambulance bay, their thinking was that the colder temperature might buy me some time. My daughter administered the medication and provided clear instructions on the procedures to the paramedics standing by.

It is concerning how little training the emergency medical teams had about my condition. I wear a medic alert bracelet and my medical information is thick with instructions and concerns and yet, when I am in a crisis, my loved one gets asked foolish questions, "Are you SURE she hasn't been drinking?"

<https://www.thestar.com/news/gta/2015/06/15/brain-tumour-survivor-draws-comfort.html>



I continue to document my medical voyages through illustrations. It is encouraging to see how my drawings inspire or explain my situation. Others with similar ailments find comfort and can describe what they are experiencing to people that care for them.

For me it is what I must do.

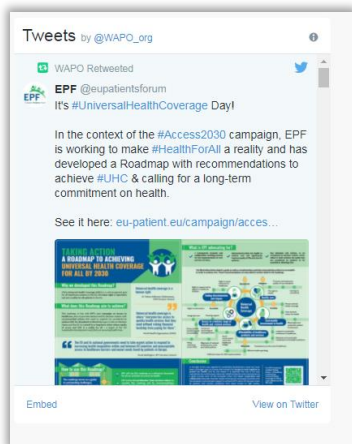


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*We encourage you to ask a clinician in your country to write an article of interest for the newsletter. And for you to spread the love yourself by contributing your story of your journey.*

*Please send to Ellen Whitton – [Ellen.Whitton@wapo.org](mailto:Ellen.Whitton@wapo.org)*

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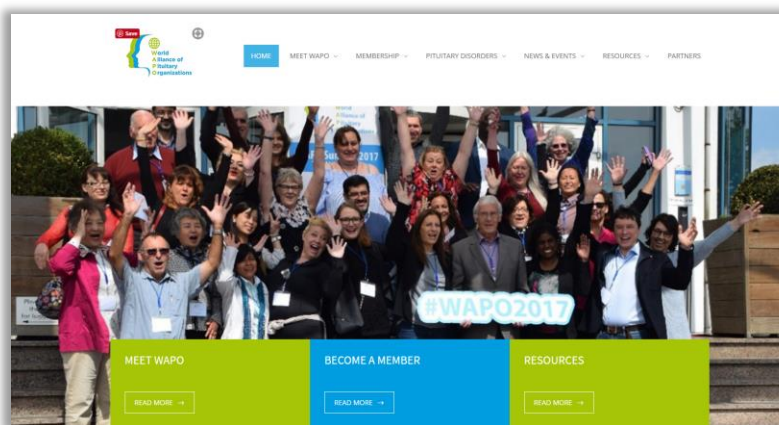
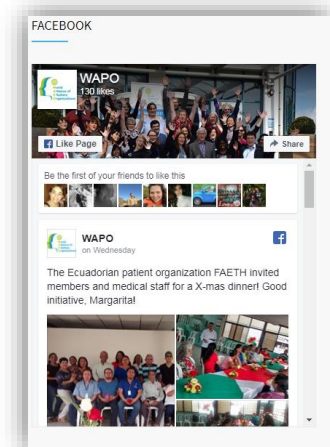
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[www.wapo.org](http://www.wapo.org) Please keep checking the WAPO website.



Screenshots from the WAPO Website 22 Dec 2017

– [www.wapo.org](http://www.wapo.org)

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