

# 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 Pituitary Patient Advocate,



Four months have passed since our live meeting in Amsterdam. We still remember the workshops at Dorint hotel on Friday and Saturday and the wind mills and the dinner on Saturday night. We have so many plans as a result of these three days. We will tell you more about them in this issue of the Global Pituitary Voice.

But before we get into the details, I would like to share some great news from Australia. Sue Kozij, a WAPO Board member, was given Life Membership to the Australian Pituitary Foundation (APF) in recognition of her 20 year-long efforts to develop the foundation. Even though Sue has already retired from the APF Board, she is still an active member of the pituitary community in Australia. Sue also plays an important role in the global pituitary patient community since its very first meeting in 2012. We all congratulate you, Sue, you definitely deserve it!

Now, just a couple of words about what you will find in this issue:

- Traditionally, there are some news from our members from all over the world. Send us your news to share your worries and hopes and best practices with colleagues from other countries.
- Global Awareness Team will share its ideas on the global awareness activities for 2017-18.
- You will get a summary from the WAPO Summit 2017.
- And, as usual, there is the calendar of pituitary related events. It is still incomplete, and it is with your help only that we can enrich it with the most up-to-date information.

We are very much interested in making the Global Pituitary Voice useful and interesting for you. Please provide us with your feedback on its content and on the format, please share your ideas on what would an ideal newsletter would look like.

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 MAGIC Foundation is preparing for our Growth Awareness Campaign scheduled for the 3rd week of September annually. Awareness of growth in Children is one of the major goals of the foundation. A worldwide campaign will begin on September 18th and continue throughout the week. In some countries the campaign will be recognized as Growth Awareness Day, September 20th.

The foundation also completed a very successful educational convention in late July, 2017, with nearly 1,000 attendees and covering several children's growth disorders and adult disorders such as Cushing's, AGHD and more.

We encourage all to help and participate in our growth awareness campaign. Visit MAGIC's web site. Click the following link for ways you can contribute to the GAC. There are many easy and quick options to help spread the word. <https://www.magicfoundation.org/Events/>

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**SOUTH AFRICA**

092-551-NPO | Public Benefit Organisation No.930038251 - **Annual General Meeting 2017**

Pituitary Community South Africa will hold its annual general meeting on August 29, 2017. Joining us for the first time will be Dr Thomas Nyirenda who works for the EDCTP (European & Developing Countries Clinical Trials Partnership) as South-South Networking and Capacity Development Manager. Dr Nyirenda is a new member on the PICOMSA board and we believe his expertise will bolster our bid to build the organisation's capacity. We will also be joined by a non-resident member who is a patient representative from Namibia as we broaden our reach to include non-residents who receive treatment in South Africa. Discussions are on-going to sell the Federation for International Nurses in endocrinology initiative to local nursing fraternity as part of a campaign to raise awareness among primary healthcare providers. We look forward to sharing the outcomes of the meeting and any new developments in the next edition.



**UNITED STATES OF AMERICA**

Patient education is the focus for The Cushing's Support and Research Foundation this year. We held a webinar in April about Quality of Life for Cushing's patients, because many of our members felt this is important. The webinar was presented by Dawn Herring, a Licensed Marriage and Family Therapist and Cushing's survivor. Dawn also writes a regular column for our newsletter. You can view the webinar on the CSR website at <https://csrf.net/conference-reports/patient-webinars/cushings-quality-life-webinar-2017/>.

On October 20th, CSR will be hosting a free Cushing's Patient Education Day in Bethesda, Maryland (near Washington, DC), at the National Institutes of Health. Learn more about the normal function of the pituitary, diagnosis of Cushing's, the effects of excess cortisol, medical therapy, recovery, quality of life after Cushing's and coping with illness. Interact and share experiences with patients and expert physicians. Contact me at [ekwhitton@earthlnk.net](mailto:ekwhitton@earthlnk.net) for more information.

Our President, Louise Pace, along with neurosurgeon Dr. Edward Laws of Harvard Medical College, have edited a comprehensive book entitled "Cushing's Disease: An Often Misdiagnosed and Not So Rare Disorder", published by Elsevier Press. This is a large and detailed book with chapters written by experts on many aspects of Cushing's, and is available in both print and electronic forms. For more information, see <https://csrf.net/books/cushings-disease-often-misdiagnosed-not-rare-disorder/>.



**AUSTRALIA**

We were very excited to learn that the submission to the Pharmaceutical Benefits Advisory Council (PBAC) for Pegvisomant to be listed as a subsidised treatment in Australia for Acromegaly was successful. The product was launched on 1<sup>st</sup> September this year. Thank you to all our international friends who responded to our survey to assemble information on the personal experience of using this medication.

A submission for Growth Hormone for severely deficient adults was submitted at the same meeting, and has been recommended by the PBAC to the government, but they are still keeping us waiting in anticipation for a statement. We will update you in the next newsletter.

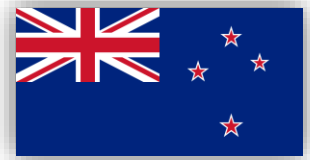
On 29th July we hosted an educational morning at a major tertiary hospital in Brisbane, Queensland. The staff at Princess Alexandra Hospital gave their time on an honorary basis. The room was packed! It was great to see a small number of nurses attending as well.



*The topics suited everyone in the room.*

**“Growth hormone replacement and its role in the adult” Prof Ken Ho, Endocrinologist**  
**“Sex Hormones” Dr Viral Chikani, Endocrinologist**  
**“Gamma Knife®” Assoc. Prof. Matthew Foote, Radiation Oncologist**  
**“Glucocorticoid replacement – what to be aware of” Assoc. Prof. Warrick Inder, Endocrinologist**  
**“The role of the endocrine nurse in hypopituitary patients” Ms Jane Sorbello, Endocrine Nurse**

As part of Pituitary Awareness Week in Australia (last week in July) we managed to get a small segment on morning radio with Assoc. Prof Matthew Foote speaking on Gamma Knife radiosurgery for pituitary tumours. A stand was set up at the hospital for patients to visit which proved to be well visited.



The New Zealand Acromegaly Society is a patient support group supporting and educating those with acromegaly and their families. We have over 100 members from all across New Zealand.

One of our goals is to raise awareness of the condition. We have made a leaflet aimed at General Practitioners. Currently we are working on an article for the Dental Association and an article for the Podiatry Association. Funds raised through our fundraising activities are used for the publication and dissemination of these awareness articles.

Overall 2016/17 has been consistently busy with the following events: We held a combined Auckland/Waikato coffee catch up at the Remuera Golf Course in November 2016 attended by 17 people.

The South Island group had a catch up at their brand new RSA in Christchurch in February 2017. Both of these events were relaxed and enjoyable and provided a chance for us all to enjoy each other's company.

We organized our "Get Active! for Acromegaly" event around International Acromegaly Day on 1<sup>st</sup> November which saw our members involved in walking, cycling, reading, running, kayaking, walking around Rarotonga and some just being active by making a donation. This activity raised approx. \$3000 dollars for our education awareness campaigns. We will be holding the "Get Active! for Acromegaly" again on 1st November 2017.



Movie night on 11th March 2017 was a great night out with drinks, nibbles, roast dinner and a thought provoking and inspirational movie about two groups marginalized by the government and society based on a true story. This activity raised approx. \$1200 dollars for our education awareness campaigns.



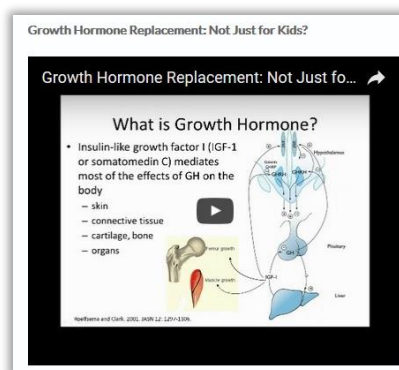
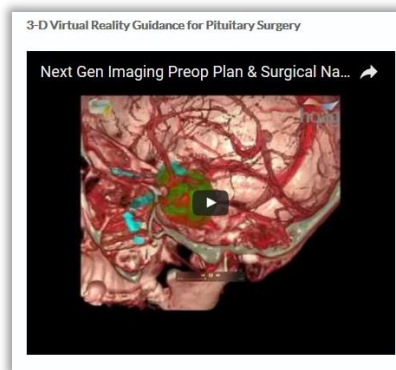
## UNITED STATES OF AMERICA

The Pituitary Network Association (PNA) has many programs and tools but the most popular and successful program is by far our Educational Webinar series. The monthly webinars are typically hosted by our professional physician members although occasionally experts in related fields will host one of our webinars. Our webinars are designed to provide information helpful to not only patients and their families but also to other health care providers interested in learning about pituitary disorders, its many co-morbidities, symptoms and the latest treatment options.

The PNA strives to provide a balance of topics to interest people with all types of pituitary disorders. People with pituitary disorders suffer from a wide variety of symptoms and health issues that encompass many different aspects of the patient and their family's lives. Our goal with our webinars is to offer information that will help patients improve their quality of life, better understand their condition, and ultimately thrive. Our webinars have an international audience and have been viewed by people in scores of different countries. Each webinar is broadcast live which offers the attendees the ability to type in questions during the webinar. At the conclusion of the webinar the questions are read to the presenter and answered live so that everyone can hear them. Viewers in different time zones across the globe have reported that the information provided is so valuable they will even get up in the middle of the night to attend our webinars.

With topics such as “Next Generation Imaging, Pre-Operative Planning & Surgical Navigation Using 3-D Virtual Reality Guidance for Pituitary Surgery”, “The Essentials: The Diagnosis and Management of Hypopituitarism” and “Psychosocial Aspects of Pituitary Disorders” the PNA offers the latest innovations as well as information on navigating daily life.

In addition to our live broadcasts each webinar is recorded which allows the PNA to prepare videos that are made available on our website at [PNA Educational Webinars](#) and on our [YouTube channel](#).



The PNA has an interactive global internet presence with our flagship website [www.pituitary.org](http://www.pituitary.org) and our online store [www.pituitarybooks.com](http://www.pituitarybooks.com). In addition, we have satellite sites [www.raginghormones.org](http://www.raginghormones.org), [www.acromegaly.org](http://www.acromegaly.org), and [www.cushings.org](http://www.cushings.org). All of our websites offer visitors valuable, reliable information to help aid them in getting a proper diagnosis and answer the many questions that arise from those diagnoses. The PNA is active in promoting “pituitary” awareness with the overall goal of an early diagnosis; shortening the time between the onset of symptoms, the official diagnosis, and treatment and recovery.



## UNITED STATES OF AMERICA

What is happening in the Acromegaly Community? We are busy! Currently our main support discussion page has about 1700 users. We interview each member questioning them on why they want to be a part of our community and are very strict with the guidelines that it has to be someone affected in some way by the condition to be a part of our group. We also have other discussion groups, such as a girls' only acromegaly discussion group, a boys only acromegaly discussion group and a family and loved ones group – where we do not allow patients so that loved ones feel free to discuss with others what it is like living with someone with acromegaly. These groups are monitored 24/7 and in our opinion, can be life changing for patients to be in a safe place to discuss issues with others that truly understand what they are going through.

Other than running our support pages we have also been busy trying to learn all that we can about acromegaly. We work with many “leaders” that specialize in acromegaly, attended the Fifteenth International Pituitary Congress and took part in forward thinking discussions regarding this condition. We’ve expressed to many that we believe this forward thinking regarding our disease will be what it takes to improve the quality of life of patients that currently suffer symptoms although their numbers are within the normal range. We also attended the Endocrine Society meeting in April with Endocrine physicians from all over the world.

Acromegaly Community was thrilled to have representation at the WAPO meeting in Amsterdam and very thankful to work with other organizations from around the world.

We are currently recruiting for a Cedar Sinai study regarding combo therapy with patients. It is difficult for physicians to find patients that might qualify for these trials and for us, it is just about spreading the word about these studies and we can usually find patients much easier and we are a great source to get the word out to patients.

There are several other recruitments we have worked on. The Somatuline Depot 10 year anniversary campaign for patients, it’s hard to believe it’s already been 10 years since approval in the USA! We have also worked on several survey projects regarding the quality of life of patients and such.

Another exciting project that is moving closer to completion is our revamp of our Acromegaly Community website! Our new site will have a few of the projects we have been working on such as “The faces of Acromegaly” portion. We feel this is important because in our opinion patients are being delayed at times in diagnosis because they are told they do not appear acromegalic enough. Our goal is to show that everyone who has this condition does not look acromegalic. Good medical care is crucial to earlier detection and possible remission.

All in all, we are flourishing. We truly wish no one had to be a part of our group and this condition was non-existent, but we have to say that we believe we have one of the finest groups of patients in the world.



## 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 [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)

### September 2017

September 4 to 10 - [Migraine Awareness Week](#)

September 8 - [World Physical Therapy Day](#)

[Growth Awareness Week](#) starts 15 September 2017, USA

September 11 & 12 - [Annual Congress on Endocrine Disorders & Therapies](#), Dallas Texas, USA

September 13 & 14 - [International Conference on Endocrinology & Diabetes Summit](#), Singapore City

September 14 - [Neuroendocrine/Pituitary Conference](#), Washington University, USA

September 22 to 24 - [National Acromegaly Conference](#), Vancouver, Canada

September 29 - [Pituitary Disease Conference](#), Abu Dhabi, UAE

### October 2017

Pituitary Awareness Month

October 4 to 7 - [Symposium on Hormones and Cell Regulation](#), Mont Ste Odile, France

October 9 & 10 – Conference on Neurology & Neuro Cognitive Disorders, London, UK

October 12 – [World Sight Day](#)

October 14 – [9<sup>th</sup> Annual Pituitary Day](#), Johns Hopkins Pituitary Center, Maryland USA

October 16 to 17 – [Global Neuroscience Conference](#), Osaka, Japan

October 19 to 22 – [EndoBridge 2017](#), Antalya, Turkey

October 18 to 22 – [Annual Meeting of the American Thyroid Association](#), Victoria, BC, Canada

October 21 to 28 – [International Brain Tumour Awareness Week](#)

October 30 to November 1 – [Neuroimaging & Interventional Radiology Conference](#), San Antonio, USA

October 30 to November 1 – [International Endocrinology Conference](#), Chicago, Illinois, USA

### November 2017

[November](#) – Mens Health Month

November 1 – [Acromegaly Awareness Day](#)

November 13 to 14 – [Conference on Neurological Disorders and Stroke](#), London, UK

November 13 to 15 – [Global Neurologists Annual Meeting on Neurology & Neurosurgery](#), Athens, Greece

November 25 – [National Pituitary Conference](#), Birmingham, UK

### December 2017

December 3 – [International Day of Persons with Disabilities](#)

December 9 – World Patient Safety Day

December 12 – [Universal Health Coverage Day](#)

## GLOBAL AWARENESS TEAM

As decided at the WAPO Summit 2017, global awareness is one of the key dimensions of WAPO activities. We have a Global Awareness Team composed of pituitary patient advocates from the UK, South Africa, Bulgaria and Russia working on the global awareness activities.

Based on the information we have in the Calendar, we have selected three points of the year to run global pituitary awareness events at:

- October as the Global Pituitary Awareness Month
- November the 1<sup>st</sup> as the Global Acromegaly Awareness Day.
- April the 8<sup>th</sup> as the Global Cushing's Syndrome Awareness Day. The day is selected as it is the birthday of Harvey Cushing (1869- 1939) – the American physician, surgeon and endocrinologist who discovered it & first reported the disease in 1932.

There must be a good reason for the choice of the Acromegaly Awareness Day and the Pituitary Awareness Months dates, we have not found it yet. If you know it please share it with us.

We have decided to announce these dates as global awareness dates and to run special events at these dates.

As the time till October is too short to prepare and run any significant activity, the next date we will concentrate on is the 1<sup>st</sup> of November 2017, the Acromegaly Global Awareness Day. We will follow all the activities you have locally for the acromegaly day in your countries and we will have a global campaign as well. There are quite a few ideas of what the campaign should be, one or two of them will be selected within a couple of weeks so that you have enough time to prepare your local campaign in line with the global one. Some of the ideas are: to run a personal story contest, to create a cartoon showing the changes caused by the disease, to let people modify their photo to look like an acromegaly patient, to take a pea as the symbol of the pituitary gland and to run a "sit in a bowl of peas" challenge, to use a well-known song as the song of the acromegaly patients, etc.

You will hear more from us soon!

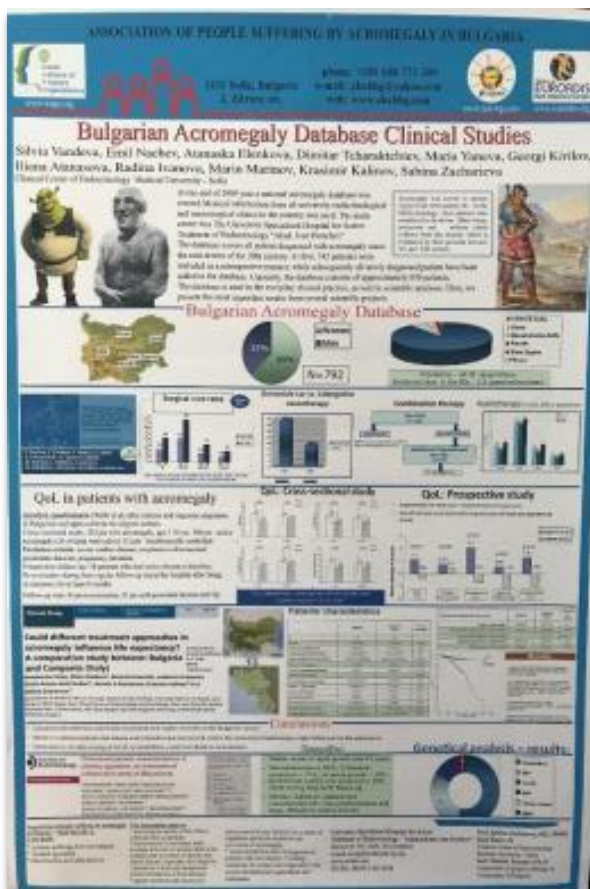
Please send your questions and ideas regarding the global awareness activities to Andrei Andrusov at [andrei.andrusov@wapo.org](mailto:andrei.andrusov@wapo.org) Your ideas and any other help is very much appreciated!



## 2017 WAPO SUMMIT SUMMARY & SAVE THE DATE FOR 2018

The 2017 Summit is already behind us for a couple of months, but it's still impressive how we made this – all together - a great success! Thank you to our sponsors, Novartis, Ipsen, Pfizer, Chiasma & Strongbridge Biopharma.

There were patient advocates from 23 patient organizations, and incl. full members, speakers and sponsors we were in total with 45 persons. Our facilitator was Mr. Jan Geissler (Patvocates/Eupati), who did a great job before and during the WAPO Summit. He suggested the Social Media Wall, which was a success! We also had 2 interpreters on Spanish-English for patient advocates from Latin America.



The 'Poster contest' was won by the Bulgarian Association of Patients with Acromegaly (ABAB), who received a certificate and their 'attending fee' will be waived for next year's Summit. After the meeting and presentations, we've asked all patient advocates to share their ideas and comments in a survey.

We wish to thank all full members who invited WAPO to come to their country for the next summit. It was hard to make a decision, but we decided to choose for Italy. At this moment, we are already working on the WAPO Summit 2018, which will be organized in Venice, Italy!

So please, **SAVE THE DATE ... April 20 – 22, 2018!**

If you did not receive the WAPO Summit 2017 report, please contact us by [mail@wapo.org](mailto:mail@wapo.org)



## PATIENT – LED CLINICAL TRIALS, LONDON (UK), MAY 8-9 2017



Did you know that one in ten clinical trials don't generate even a single patient volunteer? And how come, when there are patient volunteers, many clinical trials report low retention rates? These were some of the major questions that were highlighted and discussed during Eyeforpharma's 'EU Patient-led Clinical Trails' conference held in London earlier this year.

On May 8-9 in London, representatives from both patient advocacy groups and pharmaceutical trailblazers in patient-centric trials came together to deliver workable advice facilitate and improve not only clinical trial outcomes, but also learn from peer best-practices on successful clinical trial approaches, as well as explaining the added value that expert patients can provide from the onset of clinical trial design. Sheila Khawaja and Malini Raj attended representing WAPO.

The 2-day event offered numerous engaging sessions covering a vast range of issues such as learning to use the best social tools to raise awareness, to addressing trust issues, to location and regulatory factors which affect volunteer retention, and even strategic information was presented in a series of engaging sessions, discussing what is needed to plan patient-led trials which will improve and save lives.

Collaborative work undoubtedly increases trust and transparency, providing pharmaceutical and patient advocates the most appropriate approach and technology to produce more efficient clinical trials, bearing in mind the ultimate purpose: more effective treatments for a host of serious and life-limiting conditions, and an improvement in the quality of life of patients, caretakers and family members.

The conference and panel themes centred around the recognition of the role of patients to not only be trial co-designers, but at the centre of trial creations. When this involvement is authentic, and patients own their trial, it will result in increased retention, increase efficiencies and better outcomes.



Sheila was an invited panellist in a session dedicated to "How transparency benefits you and increases retention". Key discussions highlighted on: the increasing need of transparency in sharing clinical trial results, even if these do not have a positive outcome; With the rapid onset of m-Health, subjects participating in clinical trials also wish to know exactly how their remote data is used in a clinical trial and what happens to it; Lastly, stakeholders should also ensure that clinical trial data is easily accessible and the clinical trial summaries must be presented so that it is understandable by the general public.

Sheila also welcomed her moderator role in the very last panel session of day 1, "Get smart on trial design" where pharmaceutical stakeholders, university research units and patient advocate had an opportunity to discuss and compare the differences in trial design and patient involvement between the two stakeholders. The discussion illustrated how collaboration between pharmaceutical industry and universities has existed for some

time now; and although both stakeholders work to a better quality of life for the public, the approach and level of trust shown by patients and people in general is remarkably different. Nevertheless, both stakeholders recognized the important value of patient collaboration from the very onset of clinical trial design.



Malini participated on a panel which discussed "Capturing advocate expertise for efficient, quality-driven trials". The objective of the panel was to harness patient groups as both trial-designers and awareness raisers, and transform clinical operations through cross collaboration and diplomacy as well as adding value to trials, learn lessons on including diverse patient populations to facilitate recruitment for the common goal of best practice and high quality medicines.

Attendance at the seminar provided an invaluable opportunity to increase the awareness of WAPO on a global scale and participate and engage in the important dialogue. It also gave an opportunity to collaborate and establish relationships with key stakeholders, innovators and industry leaders, to network with industry experts and key decision makers, and learn by attending sessions from over 20 speakers comprising senior pharmaceutical representatives, fellow patient advocates and patient organizations and participate in insightful panel discussions, workshops and case studies.



## FEATURE ARTICLE: KEEPING YOURSELF HEALTHY WHILE LIVING WITH ACROMEGALY

Dr Yuval Eisenberg, MD, University of Illinois at Chicago, Division of Endocrinology, Diabetes and Metabolism, Chicago, IL

Acromegaly is a condition of excess growth hormone (GH), most often resulting from a pituitary gland tumor of GH producing cells. Patients with Acromegaly have a unique set of related medical issues, some of which are overlooked by patients or their providers. Fortunately, many of the problems discussed below are resolved or improved by proper medical and surgical treatments. However, since diagnosis is often delayed in many patients (6-8 years from onset of symptoms on average), several complications may remain for a longer duration. Being aware of the possible complications can lead to better screening, and improvement in the quality of life for patients dealing with this difficult disease.

### **Bone and Joints:**

More than 70% of patients with acromegaly have joint problems<sup>1</sup>. GH promotes growth of joint cartilage and enlargement of ligaments around the joints, which leads to cartilage thickening and narrowing of joint spaces. Only early on are these changes reversible, so for many patients, joint issues will be lifelong. Aches and pains in the large joints (hips, shoulders, knees) are most common as well as low back pain. Patients with Acromegaly are also at risk of osteoporosis (thin bone disease) which leads to higher rates of bone fractures.

Carpal tunnel syndrome (CTS) may occur in upwards of 65% of patients with acromegaly<sup>2</sup>. Many patients will have had surgery for CTS prior to their acromegaly diagnosis. Soft tissue swelling occurs at the palm side of the wrist and can lead to considerable pain, numbness, tingling and weakness in the hands. After successful treatment of acromegaly, symptoms most often do improve, but changes in the health of the involved nerve (median nerve) are often permanent and may lead to a need for surgery.

***What can I do?:*** Staying active with low impact weight bearing activities reduces the risk of fractures. Using an elliptical training machine, brisk walking and low impact aerobics are some safe and effective options. Resistance training to strengthen muscle around bones can also be helpful. Weight loss (if appropriate) can help with pain in weight-bearing joints (knees and hips). Checking and replacing vitamin D (if low) can help to improve the strength of weaker bones. Optimizing the amount of ingested calcium in your diet can also improve bone health. Medications aimed at preventing bone loss or increasing bone strength can also be used if bone weakness is severe (measured by a bone density exam).

### **Dental:**

A common issue for patients with acromegaly is growth and protrusion of the mandible (the lower jaw) that often doesn't allow proper tooth alignment. Some patients notice changes in chewing, swallowing or even speech, partly also due to enlargement of the tongue. Jaw growth can lead to temporomandibular joint (TMJ) pain (where the lower jaw connects to the skull), jaw clicking and to wider spacing between teeth. Dental problems are commonly listed as part of a reduced quality of life for patients with acromegaly.

***What can I do?:*** Regular dental visits are an important part of follow-up care for patients with acromegaly. Surgical procedures may be necessary but are best to be delayed until GH levels have been normalized. Similarly, in patients with oral appliances such as dentures, delay may avoid a need for additional fittings. Speech therapists may be able to help improve swallowing difficulties, and address speech issues.

## **Diabetes:**

The high levels of GH make insulin work less effectively in the body favoring higher blood sugars and development of diabetes in patients with Acromegaly. Medications are very often required to help maintain normal blood sugars, including insulin injections, but there are no anti-diabetic medications specific for Acromegaly. As the diagnosis of acromegaly is most often delayed by years from its start, patients may have diabetes for quite a while before their treatment, and are at risk of complications such as retinal problems (bleeding in the back of the eyes), kidney injury and development of neuropathy (nerve injury).

***What can I do?:*** Attending dietary diabetes education classes can be very helpful to make changes that will reduce weight and improve sugar control. This education is not specific to patients with Acromegaly and can often be found through the American Diabetes Association (ADA). Patients should be aware of the increased risk of worsening high sugars with the use of Pasireotide LAR (Signafor®) and discuss this with their providers. Also, the anti-diabetic medications in the class SGLT2-inhibitors have been associated with developing ketoacidosis (buildup of blood acids) in some patients with Acromegaly and should be considered when making treatment decisions<sup>3</sup>.

## **Skin:**

Skin problems are quite common to patients with Acromegaly. Thickening and swelling of the skin frequently occurs, as well as abnormal skin growths (e.g. skin tags and nevi (moles)). There is however no increased reported incidence of skin cancer. Enlargement of sweat and sebaceous glands under the skin can cause excessive sweating and oily skin<sup>4</sup>. Sweating difficulties may unfortunately not resolve completely even after control of Acromegaly has been achieved. Excessive hair growth and male pattern hair loss in women can be another troublesome complication.

***What can I do?:*** Patients experiencing hair loss may talk to their providers about topical minoxidil use. Consulting with a dermatologist may be necessary as well, especially in cases of troublesome excess sweating. Consideration of Botox injections may be helpful for severe cases.

## **Sleep Apnea:**

Obstructive sleep apnea (OSA) is a condition that occurs during sleep and is defined by short episodes of partial or complete blockage of the upper airway, often with reduced blood oxygen levels. Symptoms are often daytime sleepiness and snoring, and partners or family members may witness episodes of gasping for air or stoppage of normal breathing overnight. In Acromegaly, enlargement of the tongue and thickening of soft tissues in the back of the throat lead to blockage of the airway. Nearly 80% of patients with Acromegaly will have OSA. Unfortunately, even after successful treatment of their pituitary disease, many (upwards of 40%) will still have longstanding OSA that requires active treatment<sup>5</sup>.

**What can I do?:** All patients with Acromegaly should be screened for sleep apnea. Some doctors can order home sleep studies for sleep apnea screening, but because of how likely it is in patients with Acromegaly, a formal sleep lab sleep study will likely be recommended. Consistency with using prescribed home appliances (CPAP or BiPAP) is crucial to effective treatment. Weight loss may also be helpful in reducing apnea episodes.

### **Cancer Risk:**

Although in animal studies, GH promotes growth and development of cancers in patients with Acromegaly this isn't nearly as clear. There have been some conflicting reports of the likelihood of developing certain types of growths and cancers in people with Acromegaly<sup>6</sup>. For example, thyroid nodules (growths within the thyroid gland) are more common but the risk that they are cancerous may in fact not be higher than the general population. Small growths within the colon (large intestine) called polyps, also appear very often in patients with Acromegaly and raise some concern about risk of colon cancer. There does not appear to be an increased risk of prostate or breast cancer.

**What can I do?:** Make sure you have had your age-appropriate cancer screening. For women consideration of mammogram and pap smear and for men prostate cancer screening. Given the increase in colon polyps most guidelines recommend having a colonoscopy at the time of diagnosis<sup>6</sup>. If polyps are present repeat testing at 5 years would be recommended and 10 years if absent. If they haven't already, ask your provider to examine for evidence of thyroid nodules and consider biopsy if present.

### **References**

1. Killinger Z, Payer J, Lazúrová I, et al. Arthropathy in Acromegaly. *Rheum Dis Clin North Am*. 2010;36:713-720.
2. Sasagawa Y, Tachibana O, Doai M, Tonami H, Iizuka H. Median nerve conduction studies and wrist magnetic resonance imaging in acromegalic patients with carpal tunnel syndrome. *Pituitary*. 2015;18:695-700.
3. Quarella M, Walser D, Brändle M, Fournier JY, Bilz S. Rapid Onset of Diabetic Ketoacidosis after SGLT2 inhibition in a patient with unrecognized acromegaly. *J Clin Endocrinol Metab*. 2017;102:1451-1453.
4. Kanaka-Gantenbein C, Kogias C, Abdel-Naser MB, Chrousos GP. Skin manifestations of growth hormone-induced diseases. *Rev Endocr Metab Disord*. 2016;17:259-267.
5. Powlson AS, Gurnell M. Cardiovascular Disease and Sleep-Disordered Breathing in Acromegaly. *Neuroendocrinology*. 2016;103:75-85.
6. Katznelson L, Jr EL. Acromegaly: An Endocrine Society Clinical Practice Guideline. *J Clin Endocrinol Metab*. 2014;99:2014-2700.



## PATIENT STORY: COP, MOTHER, PITUITARY PATIENT



3-year-old Michael Johnson is about to become a big brother. But that might never have happened. In fact, *he* might never have happened – if his mom hadn't sought out the help of an expert pituitary surgeon.

Michael's mom is 37-year-old Lakisha Jones Johnson, a no-nonsense beat cop from Haledon, New Jersey with the Passaic County Sheriff's Department.

In 2012, still single and child-free, she went to the gynaecologist for a routine screening when the doctor asked how long her breast had been discharging milk. Lakisha said it had been happening for 2 or 3 years but she didn't think anything of it.

She had googled it and read that some people just lactate for no reason, that it can be harmless. But now, looking back, she realizes that she had other symptoms. She often lacked energy and focus, had missed some periods and suffered from headaches.

The O-B referred her to a specialist, who did an M.R.I. and discovered a tumor. That doctor diagnosed her with a prolactinoma and put her on bromocriptine. But her symptoms didn't go away and in fact seemed to get worse.

So she sought out a second opinion, this time from a respected neurosurgeon at the Center for Skull Base and Pituitary Surgery, and an Associate Professor of Neurological Surgery & Otolaryngology with Rutgers University-New Jersey Medical School, Neurological Institute of New Jersey.



Her doctor (who is also a member of the PNA) quickly realized that she had been misdiagnosed, and that the bromocriptine/dopamine agonist therapy was ineffective in shrinking the tumor, resulting in continued tumor growth and compromised vision from compression of her optic chiasm. He determined that instead Lakisha suffered from a nonfunctioning tumor compressing the pituitary stalk that resulted in prolactin elevation. He recommended endoscopic endonasal transsphenoidal surgery and promised to do everything in his power to save the gland and restore her fertility.

Lakisha, however, was not convinced and sought out a third opinion at a cancer center in Philadelphia. There, the neurosurgeon assured her that he had done many pituitary surgeries but warned that the pituitary gland might be compromised, and she might never be able to have children. When she mentioned her visit to the neurosurgeon, this surgeon said he had actually taken a class from the neurosurgeon, who is a respected expert in the field. So the student had the humility and integrity to point Jones back to his teacher.

Jones returned to her neurosurgeon, who performed the surgery in November 2012. The tumor was completely removed endoscopically and the pituitary gland and function was preserved. The improvement was immediate. No more headaches. Improving vision. No more milky discharge. he had so much energy, she went through with her wedding plans a few weeks later, tying the knot on 12/12/12. Two months later, while she was supposed to be on bed rest, she became pregnant with Michael.

Now she and her husband are anxiously awaiting the birth of little Mason in the end of March. She wants to thank her team. Her advice for other people who suspect something may be wrong? ***“My advice is to get a good check-up. Get the full check-up ask for the MRI. Do whatever you can to get a full screening. Because I would never have thought I was walking around with a tumor in my head. It was a real shocker to me!”***

Her neurosurgeon’s advice is to seek out an expert specializing in pituitary tumors who can differentiate a non-functioning pituitary adenoma from a true prolactinoma, because misdiagnosis by non-pituitary specialists and inappropriate treatment is not uncommon and can result in consequences of persistent tumor growth.

**Update:**

Lakisha was kind enough to share some updated pictures of her growing family. Mason Armont Johnson was born March 29, 2017.

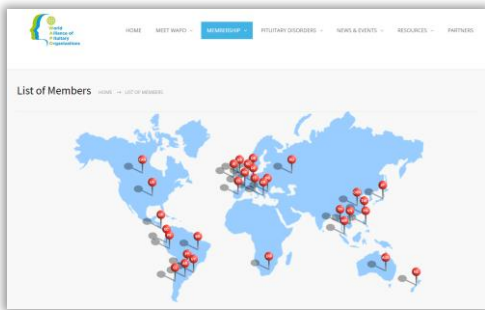


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*We encourage you to ask a clinician in your country to write an article of interest for the newsletter. And for you to spread the love yourself by contributing your story of your journey.*

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

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Screenshot from the WAPO Website 13 Sept 2017

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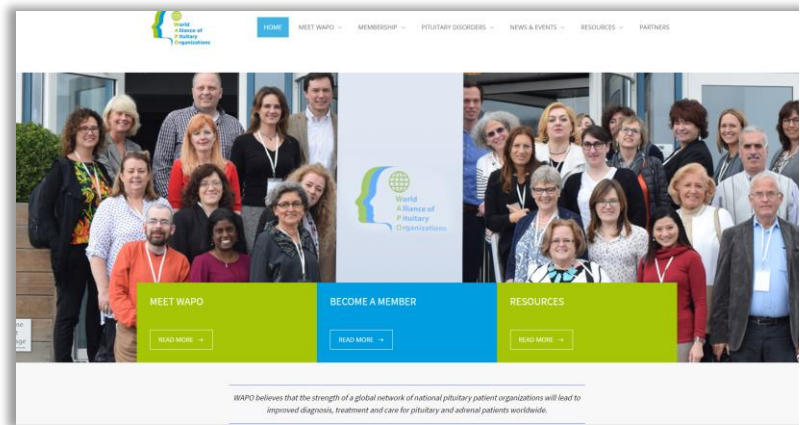
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It has come to our attention that some emails being used for internal “reply to all” communication have been incorrect or going to an “old” contact within some organisations. We ask if you wish to do a “bulk” communication to other members of WAPO, please email this to WAPO’s Secretary, Muriel [muriel.marks@wapo.com](mailto:muriel.marks@wapo.com) and she will gladly send it out on your behalf.

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