THE GLOBAL PITUITARY VOICE

JOURNAL FROM WAPO

EDITION 3 | MARCH 2017

World Alliance of Pituitary Organizations

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,

The third edition of the Global Pituitary Voice you are reading now has three main topics.

1. First, we just had the Rare Diseases Day on February 28th this year. You will find some ideas of activities linked to the Rare Disease Day as they are run in different countries. Please feel free to copy them and to address your questions to the authors of the ideas. Let's not reinvent the wheel.

2. Second, the WAPO Summit is approaching very fast. We are looking forward to seeing you in Amsterdam in May!

3. And, finally, we would like to inform you WAPO is growing and just welcomed our new 'Full members' from China, Ecuador, South Africa, Uruguay, USA, Guatamala and New Zealand. It is so exciting to have new members, new ideas and new prospective.

Hope you find this third edition of Global Pituitary Voice informative and interesting. Please feel free to share it with your colleagues and partners and send us your ideas for the next editions. And, of course, let us know how we can make the newsletters even more useful for you.

Andrei Andrusov : WAPO Board Chair

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WAPO SUMMIT 2017

We hope you all received our invitation to join the WAPO Summit 2017, which will be held in The Netherlands from 12 – 14 May, 2017.

At this moment, we are working on a Spanish interpreter and the program for the General Assembly on Sunday morning. There will be several international pharmaceutical companies attending the Summit to see how we can work together in the future. And above all, there will be a mystery dinner on Saturday evening! So, take along your walking shoes …

2016 WAPO Summit

We have patient advocates joining from a lot of countries around the world, and some new members that have joined. Some countries that have confirmed their attendance at the Summit are Australia, Argentina, Bulgaria, China, Canada, Chile, Ecuador, Germany, Guatemala, Ireland, Russia, South Africa, and many more.

If you are a patient advocate and you are an official representative of your patient organization, and would still like to join the Summit, we have some spare places!

Please let us know a.s.a.p. by email: muriel.marks@wapo.org

Thank you to our sponsors for making this Summit a very exciting and educational meeting of Pituitary Organizations!

The WAPO Summit Team

Sue, Andrei, Sheila & Muriel

WHAT SOME ORGANIZATIONS ARE UP TO

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. Below you will see some great projects undertaken for Rare Diseases Day.

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

RARE DISEASE DAY®

UNITED STATES OF AMERICA

At the Pacific Neuroscience Institute, (PNI), Pituitary Disorders Program, we recently had our first pituitary tumor support group meeting for 2017. I'm going into my 16th year as the meeting's facilitator. We recently started doing live-streaming on Facebook at our meetings! It's been hugely successful and patients from all over the world can watch and ask our speakers questions and hear from other patients.

Link to our live-stream video pituitary patient support group meeting.
https://www.facebook.com/PacificNeuroscienceInstitute/

For Cushing's awareness in April last year I asked Dr. Daniel Kelly to write a blog, but I asked him to write it for patients, not for his colleagues. I asked him to include much of what he see patient's go through and he did an amazing job. The blog had over 30K views and thousands of shares, which let me know I was right, we need our doctors that care for pituitary patients to speak up more about what patients are going through. They need to let our patients know they are being heard and medical professionals need to let their patients know they care about helping them get better, patients and doctors need to be a team. Our Cushing's blog did so well, that I wanted to give our fellow patient advocate groups from all over recognition for their hard work and dedication for patients. So, for Acromegaly Awareness, we sent out (2) blogs, one from our doctors about Acromegaly and one from me, dedicated to my fellow advocates across the globe. Again, the blog did very well. We continue to spread the word though social media and raise awareness.

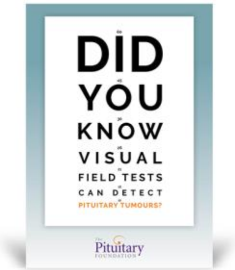
We are planning our PNI pituitary tumor symposium, this is always exciting. Neurosurgeons attend from all over the world to learn more about pituitary tumors and better treatments for patients. Education for medical professionals about pituitary tumors and hormonal disorders is a large part of what I am involved with as a patient advocate. Over the past 16 years advocating for patients with pituitary tumors and related hormonal disorders I look back at all we've done, I see so much more in the media now than I did when I was diagnosed in 2000, but even with all the hard work so many of us have done over the years, I feel we've only moved the golf ball one inch closer to the sun. We must keep talking about this disease until it becomes socially recognized and medically understood.

Ms. McGraw is a patient advocate, professional speaker and published author. As a volunteer, she facilitates the Pituitary Tumor Patient Support Group for the Pacific Brain Tumor Center http://www.pacificneuroscienceinstitute.org/pituitary-disorders/ at the John Wayne Cancer Institute. All comments are based on Ms. McGraw's personal experiences and she is not responsible for any miscommunication. Ms. McGraw is not a medical professional. Always consult your own medical doctor.

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.

Our Autumn campaign, to coincide with Awareness Month targeted opticians, and many patients participated by giving awareness talks, distributing leaflets to their local opticians and holding ‘Great Pituitary Bake-Off’s’. The Foundation contacted optometry organizations, optician headquarters, eye hospitals and retinal screening centers.



DID YOU KNOW VISUAL FIELD TESTS CAN DETECT PITUITARY TUMOURS?

The Pituitary Foundation

We have continued to speak out for Pituitary patients due to our involvement in the NHS England Clinical Reference Group, and the Chair of the group who is responsible for re-writing the Service Specification for Pituitary disease in England has requested direct input from our organization. Consequently, a paper has been prepared and will be presented at the next meeting. Similarly, our organization is a member of the Welsh Cross Party Group, and following participation in a focus group we were able to contribute to the Welsh Charter for Rare Disease Patients. On Rare Disease Day, one of our Volunteers visited the UK Parliament to highlight Pituitary conditions.

We were delighted that more than 1,000 people took part in The Pituitary Foundation Survey last year, and analysis is currently underway by research students at Plymouth University. However, early dissemination of the results demonstrate the impact pituitary conditions have on health, employment, personal relationships, well-being and quality daily life. This information will be used to target future campaigns and continue to raise awareness amongst healthcare professionals and the general public. The initial results have been published in the latest edition of Pituitary Life, our quarterly magazine for members.

Fatigue Management information continues to be both sought after, and well received. Our patient and Family Services Coordinator, Sammy Harbut continues to visit Local Support Groups throughout the UK to talk about this subject, and has also been approached by Addenbrooke’s, hospital (a center specializing in treating pituitary conditions) to present on this important subject. We are currently working to produce a ‘fatigue management’ webinar, and hope to launch our first live webinar by the end of March. This will provide all patients and their families an opportunity to learn more about fatigue, and develop strategies to manage it more effectively.

Sammy was also asked to deliver a lecture to third year Occupational Therapy students at Liverpool University, when WAPO and its work was discussed. The students showed considerable interest in both Pituitary conditions and how they impact on patients’ lives, and also how Occupational Therapy is being used and developed in this non- traditional setting.

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THE NETHERLANDS

In the first edition of the WAPO newsletter ‘the Global Pituitary Voice’, the Dutch Adrenal Society NVACP and AdrenalNET informed you about the research survey to caregivers. The survey was held during May – September 2016. Now the responses are analyzed and would we like to share them with you.

From about 1400 requests, we received 204 surveys in return by the caregivers of our members, who are partners or relatives. 30 of them asked about the definition of ‘caregiver’. In our patient organization, most of the caregivers take care of someone with adrenal insufficiency (71%), CAH (11%) and Syndrome of Cushing’s (11%). On primary hyperaldosteronism (5%), Pheochromocytoma and adrenal carcinoma both 1%.

We like to share some general outcome and ideas of the conclusions.

The aim of the survey was to investigate:

1. How much help people with an adrenal disease would receive?
2. Who is the caregiver?
3. What kind of help do they give?
4. What kind of help is asked by the patient?
5. What problems does the caregiver have?
6. To learn about tips & tricks from experienced caregivers towards ‘newcomers’.

93% of the respondents say; ‘It’s no question to be a caregiver!’ The amount of time, which caregivers give help in a week is from 8 - 29 hours per week. 70% of the caregivers do not receive support - in any way - by third parties. People who are a patient, but live alone, seek a ‘caregiver’ among friends, neighbors or relatives living nearby. All caregivers answer ‘provide caregiving is rewarding’. A relatively small percentage indicates that helping and caring is physically (15%) and mentally (11%) demanding.

Difficulties caregivers meet are:

a) loosing their own activities (61%)
b) no boundaries (55%)
c) caregiving increases over time (>8 - 29 hrs a week)
d) overload by physical or mental strain (>25%).

We received the following tips from caregivers to caregivers:

1. Be honest to each other regarding expectations and need.
2. Provide your own activities to load and move your sights on.
3. Seek help with care, so it doesn’t all end up on one shoulder.
4. Set personal boundaries and sometimes say 'no'.
5. and sometimes: Discuss the situation at work, so that the manager is aware what is involved.

WE HOPE THE ABOVE GIVES YOU SOME INSIGHT IN THE WORK AND SUPPORT BY CAREGIVERS IN THE NETHERLANDS!

LINKING PEOPLE WITH INFORMATION
AUSTRALIAN PITUITARY FOUNDATION Ltd

AUSTRALIA

Rare Diseases Day in Oz.

Australian Pituitary Foundation themed its latest newsletter around Rare Pituitary Diseases. The content gave statistics on the estimated incidence and prevalence based on 2017 projection from the Bureau of Statistics. It also contained patient stories and tips from a psychologist on how to “handle” the emotional turmoil of being diagnosed with a rare condition.

ACROMEGALY:

Incidence: 0.34 new cases per 100,000 population per year (approximately 82 Australians every year)
Prevalence: 8.6 cases per 100,000 population (approximately 2,089 Australians affected at any given time)

CUSHING’S DISEASE:

Incidence: 0.17 new cases per 100,000 population per year1 (approximately 41 Australians every year)
Prevalence: 1.2 cases per 100,000 population (approximately 291 Australians affected at any given time)

CRANIOPHARYNGIOMA:

Incidence: 0.13 new cases per 100,000 population per year (approximately 32 Australians every year)
Prevalence: 2 cases per 100,000 population (approximately 486 Australians affected at any given time)

DIABETES INSIPIDUS:

Prevalence: 4 cases per 100,000 population (approximately 972 Australians affected at any given time)

OTHER RARE PITUITARY DISORDERS:

: *Sheehan’s Syndrome*	My Virtual Medical Centre - Sheehan's Syndrome Link
: *Lymphocytic Hypophysitis*	Medscape Article - Requires Login
: *Empty Sella Syndrome*	NORD - Empty Stella Information
: *Congenital Panhypopituitarism*	PDF - How to Treat Congenital Hypopituitarism

We also launched competitions for patient stories and photos themed around The Join and Raise Hands! Initiative. http://www.rarediseaseday.org/join-your-hands We asked to start our own Aussie version of a picture joining and raising hands, ideally including something that is typically Australian in the shot as well.

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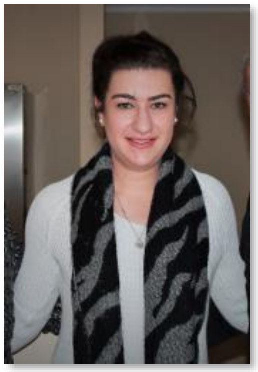

Amanda featured her story for APF.
L to R:
Puffed up with Acromegaly
6 months after injection therapy
Feeling so much better now

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TIPS ON HOW TO COPE WITH THE DIAGNOSIS OF A RARE DISORDER:

Written for Australian Pituitary Foundation by Lynne Gibbs, MAPS, Psychologist.

Once you have received a diagnosis of a rare pituitary condition, there is a number of possible emotions that you may feel, both immediately after the diagnosis and in the longer term.

Some possible emotions that you might feel following a diagnosis of a rare pituitary condition are;

- Relief: That you finally have an answer to what has been wrong with your health
- Anger: This could be anger at health care professionals, at yourself, or your religion's God
- Fear: Fear often results from not knowing what is going to happen
- Disbelief: There can be a sense of shock that this is happening to you
- Loneliness: Having a pituitary condition can make you feel lonely, that no one understands what you are going through. This may also result if your condition is making it hard for you to get out of the house and socialise
- Loss of Control: All of a sudden it can feel that your life is out of control and you may have to make decisions quickly about things like treatment options
- Distress: It is very common to feel distress about your diagnosis and others close to you might also feel distressed
- Sadness: It is very normal to feel sadness, however if this sadness continues in the longer term with other symptoms, it might be a sign of depression

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Helpful ways of coping with your feelings include:

- Talking to others: This might be a friend or family member or a professional like a GP or psychologist. It is important to find someone to talk to who will really listen to what you are saying and not judge you. It does not help when you talk to someone about your inner most feelings and they say things like you are 'crazy' or you do not have the right to feel that way. If you want to find a psychologist in your area, check out the Australian Psychological Society web site at www.psychology.org.au
- Join a support group: You will be able to talk to people who are in very similar situations to yourself and hear about how they have coped with similar situations
- Do not let your pituitary condition define you as a person – remember you are more than a medical diagnosis. Think of all the different roles that you have in your life, for example son/daughter, friend, and partner. There is more to you than your pituitary condition
- Taking time out: With some emotions, like anger, you might need to take some time away from the situation to let yourself calm down before you can go back and calmly discuss the issue
- Distraction: When we are consumed with our emotions we might need something to distract ourselves so we can calm down. Examples include listening to music, tasks around the house, and calling a friend
- Humour: Could be called a form of distraction. Humour cannot take away our feelings or the problem however it can help take the intensity out of the situation and helps to calm us. Some people find that it helps them to name their pituitary condition or the cause of their condition, such as Amanda (patient story) has done. For example, naming the tumour Tom and making jokes about how Tom is going to be evicted from your head. Younger people might even like to make a silly/funny picture about what their condition looks like, for example giving it funny types of body parts like 5 legs
- Relaxation: There are many different forms of relaxation such a meditation; however the easiest to learn is deep breathing. This is breathing from the bottom of your lungs. To check if you are doing this. Place one hand on your chest and the other hand on your stomach. Your hand on your stomach should be moving more than the hand on your chest. Also slowing down your breathing, so you breathe in to the count of three seconds and breathe out to the count of three seconds. This has the effect of shutting down the stress systems in your body.

The take away message is that your feelings to receiving a diagnosis of a rare condition will be unique. You are likely to fluctuate between different emotions. There is no right or wrong way to feel. What is important is that you manage your emotions in helpful ways and there are people to help you if you need it.

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SOUTH AFRICA

Pituitary Community South Africa held its general meeting on December 15 2016 after a couple of years in the doldrums. Central on the agenda was the implementation strategy for the flagship **"Nip it in the bud"** project which is a campaign to improve treatment outcomes and lessen the impact of pituitary tumors through early detection and subsequent professional medical intervention. We believe that through enhancing the visibility of Pituitary Conditions in our communities and by educating citizens and primary healthcare providers, everyone would be on high alert and look out for signs of pituitary conditions which may lead to quick referrals and eventually early specialist intervention.

Study has shown that a large majority of the patients (over 90%) that are diagnosed with pituitary tumors in South African healthcare facilities come from ophthalmology department having been through optometrists and primary healthcare providers with over two (2) years of progressively deteriorating visual acuity. Due to late presentation, the tumors tend to be very large and expansive hence presenting the medical professionals with a huge hurdle in trying to achieve successful therapeutic outcomes. This is also a general observation in other parts of Africa and could be attributed to lack of insight into the intricate nature of pituitary tumors leading to misdiagnosis, a lack of access to healthcare facilities especially for people living in remote areas, patient apathy and cultural beliefs. This year is ear marked for building capacity and extending our structures to enable us to successfully implement our project.

The success of our project will be measured by improved results or statistics with regards to the scenario described above. Our partnerships with medical students working in our referral or tertiary centers will help in collection and analysis of data and compilation of literature on pituitary conditions in South Africa which is presently very limited.

We are also exploring ways of working together with other local organizations like the Mobile Eye Unit which conducts community outreach programs every October to promote eye care awareness with a view to creating integrated pathways and linkages for referral of patients showing signs of deteriorating visual acuity to tertiary centers.

Pituitary Community South Africa believes in harnessing the power of numbers to achieve common goals therefore we have joined hands with other organizations across the world in observing Rare Disease Day. We have been friends of rare disease day since 2009 and over the years we have taken part in the promotion of awareness of rare diseases mainly through social media platforms.

Our activities are mainly centered in Cape Town and Johannesburg however we hope to extend our structures to cover the whole country within 18 months.

Friendship Lasts Longer than Illness-Sidelights of Gathering in Hangzhou *by CAPA Ward Mates of Zhejiang Province*

It was at 2 pm, November 5th, 2016; the heaven-like Hangzhou is in the best time of autumn. Alongside the streets around the West Lake, there were golden fallen leaves, which seemed even more beautiful. The gathering of ward mates from Hangzhou started in the Zhongshan International Hotel located in downtown Hangzhou. This event has received a lot of warm response from ward mates in Zhejiang province. With the arrival of the ward mates, the gathering gradually warmed up, all greeting each other. Due to similar medical experience, they felt so connected.

In addition to the ward mates, there were doctors from the Department of Endocrinology, Department of Neurosurgery and Department of Radiotherapy in the gathering. The doctors explained the diagnosis and treatment of Acromegaly to the ward mates and answered their questions. And during the gathering, representatives from Ipsen interpreted the Medical Insurance Policy in regard to the medication for the ward mates.

The gathering was warm from beginning to end. It lasted for more than five hours, and was finally ended in the joyous atmosphere of the dinner. After the gathering, the ward mates gave high praise through feedback of discussion and return visits, all claiming to have gained a lot and looking forward to meeting again.

Above: Self Introduction of Ward Mates

Right: Lecture and Q&A by Doctor Yan Wei from the Department of Neurosurgery of the Second Affiliated Hospital of Zhejiang University School of Medicine

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WHAT HAS THE COMMITTEE BEEN UNDERTAKINGFOR WAPO

EUPATI 2017

Muriël Marks-de Korver and Sheila Khawaja joined the Eupati 5 year project ending meeting in Brussels, Belgium in December 13 and 14, 2016.

The final Eupati conference was a very special event for the EUPATI community, as they will take the opportunity – almost 5 years after the start of their project, not only reflect on their accomplishments, but also to prepare for future growth in order to receive a better health future through patient-focused research and development.

Above: Photo taken from Eupati 2016 – *A Board to Build a Better Health Future*
Below: Muriël Marks-de Korver (Left) and Sheila Khawaja (Right)

BY LAWS AND GOVERNANCE DOCUMENTS

A team on the Board have been working hard on the By-laws and Best Practice documents of the Organization. Thanks so much to Sonja Durinck for initially drawing up these documents. Besides from the late night/early morning teleconferencing (due to international time differences) it has been positive with robust discussion around these requirements.

ANNOUNCEMENTS

Are you interested in sharing your story of living with AGHD?

Snow Companies is a leader in patient storytelling, working on behalf of a Pharmaceutical Company to find Adult Growth Hormone Deficiency patients who are willing to share their experiences with others at an Advisory Board Meeting. The goal of the meeting is to better understand the patient journey of those living with AGHD so that the company can help support, educate and serve the AGHD patients and the healthcare professionals who treat them.

Please call the Snow Companies at 1-844-747-1619 or email us at AGHDstory@patientstorycompany.com to learn more about this potential opportunity.

Research on Cushing's by Dr. Jitske Tiemensma, USA.

Last January 2017 WAPO received a request by Dr. Jitske Tiemensma from the University of California Merced, who is doing research on Cushing's Disease. We received this request through our full member CSRF. WAPO sent the invitation letter to the Cushing's survey to her members and we hope you all joined the Survey?!
We are all very interested in the outcome – probably mid 2017 - and we'll keep you informed.

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WAPO CALENDAR OF EVENTS

WAPO has introduced a Calendar of Events, so all the necessary information on what's happening around the globe is available for all the guests. 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.

The WAPO team has been working very hard for you – but we do need some help. Is there an organization who can take on this task, or have a volunteer who can help us? The task is not too hard, especially if you like sourcing relevant pituitary information.

If you are interested in becoming a valued volunteer for WAPO (through your organization) *please, please, please* email Sue – Sue.Kozij@wapo.org

A TRIPLE ARTICLE LOOKING FROM THE VIEWPOINTS OF A PATIENT, A PSYCHOLOGIST AND AN ENDOCRINOLOGIST - *This article has been reproduced with the kind permission of The Pituitary Foundation.*

The patient explains his experiences

I am 56, and some significant things have happened to me. These changes came about purely through my persistence in seeing my GP and contacting the hospital, again and again.

I have been on growth hormone for a number of years and as far as I was concerned there were no problems. However, what I was not told was that my growth hormone levels were very high. They had been for a few years.

I was often at the GP surgery and the doctor did another range of blood tests, to try and find out why I was having terrible joint pains in my legs, hips, knees, wrists and hands. I was also very tired all the time and looked exhausted. All other tests had come back as normal. I had spoken to the hospital more than once. My GP was of the belief I may have had myasthenia gravis.

When the blood tests came back, my GP showed me them. All the tests were normal except growth hormone (IGF-1) which was extremely high.

I spoke to the hospital and after a long discussion I was told the assay (the descriptors that give the range in which the growth hormone is assessed) were not very accurate. That although the results looked high, they were not high. This confused me. How can a blood test be assessed properly if the assay is no good?

So, my growth hormone dose was reduced by half. Within a few days, the change was significant. Almost all the pain had gone in my joints. I felt better and able to do more. I did ask the specialist what long-term damage may have been done as a result of a few years of being overdosed on growth hormone, but no one could tell me.

However, I was becoming very tired, very quickly, and despite putting it down to the condition, it got worse. Around the same time my Testocaps (testosterone replacement capsules) stopped being manufactured and supplies dried up. I had to look for an alternative quickly.

In the next paragraphs, I am going to talk about the effects on testosterone on men. I will be as appropriate as possible!

When supplies of Testocaps stopped, I had to change over to testosterone gel. The gel burnt my skin and caused me much embarrassment. I had gone onto the recommended dose, but this was not monitored closely enough. On one occasion, I experienced an agonizing erection for seven hours, and was both scared and embarrassed. I rang the endocrinology department at my hospital but when I explained the problem, it was met with amusement, leaving me upset.

Fortunately, Testocaps became available again, and I had a full range of fasting blood tests done for my new Consultant, including my testosterone levels. However, these levels had not been checked for over five years as my previous consultant said it was a very complicated test.

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The psychologists view: Healthcare Frustrations

By Dr Sue Jackson

Peter’s story is, sadly, not uncommon. While there are lots of examples of good monitoring and healthcare provision, there are also lots like this one, where things go wrong.

I’m all for patients having access to their test results, but if the patient isn’t told about the limits of the tests that are being used to monitor their condition, then that sets both parties up for potential problems later on. Part of the problem with diagnosis is that symptom clusters overlap, and so it can be very hard to determine exactly what it is that’s causing the feelings the patient is experiencing. I do think, though, that it’s particularly difficult for pituitary patients. The endocrine system is particularly complicated, and getting a good working knowledge of your condition can be very difficult. How are patients supposed to know what tests are needed and how to interpret those results? Lots of patients with chronic conditions find that they have to become expert in their levels of knowledge, but not all healthcare professionals acknowledge their expertise, while some others just assume an appropriate level of knowledge in their patients which is fine if they’re right, but if they’re not, it leads to problems.

I don’t think that some healthcare professionals understand how having a pituitary condition affects a person’s relationship with their body, and what that means for them. To be told you have a brain tumor has to be one of the most shocking things that can happen to someone. Radiotherapy is a particularly difficult treatment to undergo, and the long-term effects, as Peter says, are profound not just in terms of physical functioning, but also in terms of psychosocial functioning, too. Many of the patients with whom I work often confess that they don’t trust their body any more. It has let them down badly and they’re not sure what it’s going to do next. They live in quite an anxious state which affects everything that they do. They can never relax and trust that everything will be OK.

Every day in many ways, your body will give you information about what’s going on with it. In the context of a fearful and untrusting relationship with your body, how do you know how to interpret that information? Remember, post-treatment, pituitary patients are living with a changed body. Hormone replacement therapy may be effective, but equally it may not be, or it may require some finessing. It can be very difficult for patients to know what symptoms to report to their GP/specialist. As Peter says, it’s not just about one domain of life, it affects everything, but a lot of healthcare is focused on purely physical functioning, and patients can feel discouraged or prevented from talking about their other signs and symptoms that something is wrong.

I think it’s particularly difficult for men. When psychologists design questionnaires (aka psychometric tests), we often look at how the different genders respond to the questionnaire. It’s very hard to get men to take part in such research, but when we do, we often find that their scores are often very different to those of the women who take part.

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Endocrinologists view:

Professor John Wass

Patients and doctors are equal. Only the patient knows the symptoms and the doctor knows about endocrinology - and so can the patient know about endocrinology. Going to outpatients is like preparing for a meeting. You need to prioritize the symptoms that are topmost and make sure these come out first. Chest pain is obviously important but loss of the outer third of the eyebrows is not going to affect quality of life or life-expectancy. Take a list if necessary. You should know what you want to get out of the meeting with your doctor. It also helps to take a relative or a friend.

All patients are different. If you are organized about the outpatient clinic appointment, they are more likely to be. You need to feel empowered. I think taking an interest in your condition is important. You should check your doses and your results. You should probably see your results and make sure they are satisfactory. You can get copies of them together with the copies of the letter your consultant has written; there should be a clear plan with your consultant of what you are going to do, and what the plan for monitoring treatment is. This should be clear to you, as well as to the person looking after you.

If you are not happy, then you can politely but firmly do something about this. The consultant or registrar should listen and act. If you are seeing the registrar you can ask to see the consultant or you can see another consultant. This is all within your rights. This can all be done non-aggressively.

These are some of the ways in which you can ensure that there is a satisfactory outcome to your consultation and your satisfactory progress generally.

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 Muriel Marks.

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ABOUT WAPO

The World Alliance of Pituitary Organizations (WAPO) is a self-governed non-profit organization created in order to unite the international pituitary patient community to push for optimal treatment and care for all patients with pituitary and related conditions worldwide. The goal of our organization is to share information, work together and support all pituitary patients' advocates, to the benefit of all pituitary and adrenal patients worldwide.

WAPO has a great potential value for pituitary patient advocates, as it will serve as:

- The united global voice of patients in global and national policy making;
- The point of concentration of correct, evidence-based information on pituitary and related diseases;
- The center of best practices of pituitary advocacy organization and operations;
- The driver of global pituitary awareness activities.

WAPO MEMBERS

Screenshot from the WAPO Website 13 March 2017

– www.wapo.org

CONTACT US

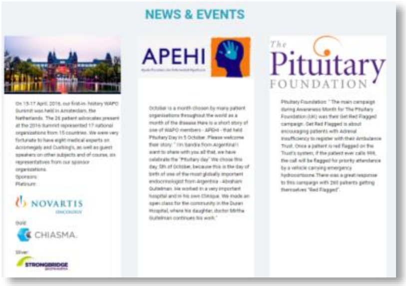
World Alliance of Pituitary Organizations (WAPO)
+ 791 757 916 20
mail@wapo.org
Facebook.com/WAPO.org/
www.wapo.org

FACEBOOK

www.facebook.com/WAPO.org Glad to see people are using our Facebook. Please keep informing us of new activities within your country and remember to “like” and “share”.

WEBSITE

www.wapo.org Please keep checking the WAPO website, which we are changing regularly. Hopefully, soon we will have a members’ area, where members can view resources and videos taken at the 2016 Summit.



As a member, we ask that your organization participates in WAPO to help achieve the vision we all discussed at the Summit. We have much work to do, and cannot do it without volunteers – if we share and take on one job per organization, we feel confident that we will have most projects underway or completed before the 2017 Summit. Soon we will be contacting each organization to see how they can assist in building the dream we all need so badly.

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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