

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.



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CHAIRPERSON'S REPORT

Dear WAPO members and friends,



I still can't get used to the variety of countries and cultures we have in our WAPO family. While we are melting under the summer sun in Europe, it is the middle of the winter in South America. And the very term "winter" is not the same in Columbia and in Russia. So many differences. And yet, so many similarities, for example, in issues related to pituitary diseases. This is what makes our community so united. We also become even closer when we meet in person at the Summit.

Just over a month ago we met in France at WAPO Summit. As we are already used to, it was a productive and inspiring meeting with many insights resulting from the presentations made by patient advocates, doctors and nurses. Together with fine French food, this was an outstanding experience. More details on the Summit are provided in this Newsletter, and you will receive a full Summit report later this month.

From all the continents we receive news about pituitary related events and actions. In this Newsletter, there are news from Americas and Europe, including Lithuania represented by AUŠVIS association, a new WAPO member. Great ideas for campaigns aimed as patients' quality of life improvement came from Ecuador. As I am focused on impact measurement, I invite you to check the extraordinary analysis of awareness campaign efficiency produced by the Bulgarian patient advocacy.

In the feature article today the link between exercise and endocrine system is analyzed by Hayley Darke. You will learn how exercise can support treatment of pituitary conditions. And a patient story will prove this too. If you however do not see any way exercise can be part of your regular practice, jump directly to page 26, it will help you to take it easy.

Don't forget to share this Newsletter with your members and partners and to contribute to the next Newsletter!

Best wishes,
Andrei Andrusov
WAPO Board Chair

WHAT SOME ORGANIZATIONS ARE UP TO

We would like to thank those who keep us informed on what your organization has been up to, if you have something you want your organization to share; please email Editor@wapo.org



LITHUANIA

ASOCIACIJA AUŠVIS

On June 15, 2019 the Lithuanian Patients Association for Acromegaly and other Pituitary disorders came together to give attention to the National Acromegaly awareness day.

The WAPO declaration (Lithuanian version) was adopted as the basic guideline for the future activities for our association. Please, find the text of the Declaration in Lithuanian and some photos from the Conference attached below

More detailed information about the event - will be provided later.



Danutė Puchova – Ledniovė – 17 June 2019



THE PITUITARY FOUNDATION



UNITED KINGDOM



Well it has been a very busy Spring for us here in the UK, as we are celebrating the 25TH Anniversary of our patient organization being formed this year. To celebrate, on April 27th we held our National Conference in Bristol, which is where our charity began, and where our National Support Office remains.

The Conference attracted 245 delegates, and we were fortunate to have some of the leading Endocrinologists attend and present including Professor John Wass, Professor John Newell- Price, Professor Stafford Lightman, Professor Steve Ball, Dr Stephanie Baldewig and Dr Karin Bradley. We held workshops for delegates in the following areas:

- Newly diagnosed patients,
- The psychological impact of pituitary conditions
- Management of common symptoms
- Diabetes Insipidus
- Adrenal insufficiency
- Your relationship with your GP & Consultant.



The highlight of the day however was the Q & A session when patients were given the opportunity to ask the experts anything of relevance, and have an immediate answer. This was a popular agenda item, and something all delegates have been complimentary about. Feedback from the day has been very positive, and inspired many. Our National Conferences are always well attended, but this year was extra special because of the Anniversary theme.



Every delegate received a special edition 25th Anniversary bag, in addition to their delegate pack, and the atmosphere was positive throughout the day. All our staff worked hard to make the day such a success, but we could not have done it without input from some of our amazing volunteers who helped prepare Conference materials, manned stands and directed and supported delegates on the day.



Following the success of the Conference in the day, it was a quick turnaround for the Anniversary Gala Dinner we held in the evening.

Many of the delegates and Doctors from the Conference joined us in this formal event, when Pat McBride, head of our Patient & Family Support team was presented with a long service award. Pat has been instrumental in the growth and development of the Charity for the last 25 years, and has held several positions, eventually becoming the Head of Patient and Family Services Team. We also recognised and thanked our volunteers for their dedication and commitment, presenting each of them with a small gift.

The evening, which began with a champagne reception, was a great success, and we enjoyed a live auction, fun photo booth, a magician performing tricks for each table, lots of music and dancing and fine food.



No sooner had I recovered from the Conference, I attended the Annual WAPO Summit in Lyon from 17th-19th May.

It was lovely to meet up with the members of the Board again this year, and I was inspired over and over by the comprehensive programme, fantastic Speakers, and enthusiasm and tenacity of the patient organizations represented. Definite highlights for me were hearing about Best Practices, and participation in the ESE Nurse 2019 Pre-Conference session. Every session was valuable however, and I appreciated the increasing emphasis on clinical research to improve patient's lives. Both evening events were very enjoyable, and to see delegates from around the world coming together with the shared aim of improving lives for pituitary patients very satisfying.

As a result of attending the Summit this year, the Pituitary Foundation are looking forward to developing closer links with WAPO and partners, and hope to welcome Sheila Khawaja to the UK for a few days in August 2019. In addition, we hope to work with J D Faccinetti to share information and resources with a more global audience.



Sammy Harbut - June 2019



PITUITARY & ADRENAL ORGANIZATION



BULGARIA

In Bulgaria, the 'GrowInform' project is a very successful project of our paediatric endocrinologists. They made an informational campaign and travel through the country. As a result, they find and start to treat children with very rare endocrine diseases connected with growth problems.

Our organization supports them with spreading of information.

GROWINFORM – A CAMPAIGN FOR EARLY DIAGNOSIS AND TREATMENT OF GROW DISORDERS

In 2014 Varna Pediatric Endocrine Society started a program for timely diagnosis and treatment of stature deviations in children. GPs with 23 058 children under their care were trained and provided with a specialized auxological software to warn them for any stature deviations. From the expected 692 children (3% of the total) only 33 were sent for further evaluation (0.14%). This result lead to a new campaign of campaign of Varna Pediatric Endocrine Society - GrowInform. GrowInform 2017-2019 is a project to identify and assess children with growth deviations, and also to raise awareness of growth. Physical growth monitoring is an important step in monitoring children's health. Growth slowdown, even accelerated growth, can be an early indicator of an underlying medical condition. Growth monitoring over the time is essential because it helps to identify trends. For 2 years, GrowInform had activities in 13 regional cities with a total population of 565 531 children (1 to 19 years). To increase participation rate in each region, GrowInform worked in partnership with more than 100 media channels and social networks (Facebook, www.growinform.org, radio, television, Internet news sites newspapers, etc.). With the help of a PR specialist organized video media, Interviews and publications with information about the visits in targeted areas weekly. Dedicated symposia and public lectures were presented during the outreach clinics. The goal was to identify and if necessary, refer for further evaluation children with growth deviations from areas with no easy access to endocrinologists.

GrowInform created friendly and positive media environment and the number of referrals increased substantially.

The vast majority of patients received information for GrowInform campaign from Facebook (36.29%), followed by Internet based media (27.01%) and General Practitioners' referrals (12.65%). Radio/TV channels (12.24%) and peer referrals (11.81%) were less presented. A total of 237 children were consulted at a mean age 6.7 years; 97 (40.9%) children were directed for further evaluation. A total of 69 (29.1%) children were fully assessed and their diagnosis finalized; 22 (9.3%) of them commenced GH therapy; 47 (19.8%) are still followed up or the tests are pending. Further 4 children with Prader-Willi syndrome were diagnosed at neonatology clinics after a dedicated symposium at a national meeting and commenced GH treatment at the age of 5.7 (11 months to 12.5 years). The age at start of therapy decreased from 8.7 years in 2016 to 7.3 in 2018. Some children with rare syndromes received definitive diagnosis and treatment: 3 children with Silver Russell syndrome, 1 with Prader Willi syndrome, 3 children with Turner's syndrome and 1 boy with 45X0/46XY, 2 children with Nounon syndrome, Leopard, Family with Albright syndrome (pseudohypoparathyroidism).

GrowInform campaign was an effective tool to improve growth deviations diagnosis and treatment. To prolong the campaign effect, a strategy for publication of educational and growth patient material is under development.

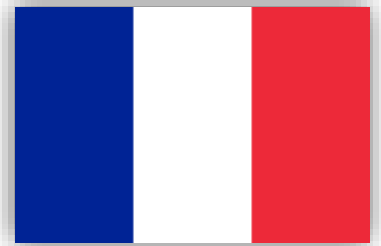


Vania Dobрева - June





ASSOCIATION SURRENALES



FRANCE

The Association SURRENALES is going to finance a project of four students from the Paris DESCARTES UNIVERSITY.

Organoids are a promising tool to replicate key structural and functional features of human organs. Recent developments in organoids to model the liver, biliary tract, and pancreas have the potential to advance regenerative medicine.

Regenerative biology is valuable for tissue renewal and replacement, but is also critical for creating models that replicate human organ physiology and functions. These models would make it easier to study the molecular and cellular features of human diseases and to develop new drugs for debilitating conditions.

Organoids are three-dimensional (3D) miniature versions of a target organ. They are a promising tool to model organ function, and are poised to revolutionize medicine. Organoids can contribute to the understanding and treatment of debilitating diseases that arise in particular organ systems, but their use is fraught with challenges.

<http://www.leetchi.com/c/soutenez-4-etudiants-pour-faire-avancer-le-futur-de-la-medecine> give you the link and the French version.

Joëlle Souche - June 2019



ECUADOR

Paseo de integración de miembros de FAETH, a la Península de Santa Elena

Pasamos un día muy lindo disfrutando de las playas de Santa Elena , su deliciosa gastronomía, momentos de esparcimiento y diversión entre amigos.

Walk for integration of FAETH members, we went to the Santa Elena Peninsula

We spent a very nice day enjoying the beaches of Santa Elena, it's delicious cuisine, moments of leisure and fun among friends.



9 de Abril - Día Mundial de la Salud

Por el Día Mundial de la Salud, **FAETH** fue invitada a la casa abierta organizada por el **Hospital de Especialidades Guayaquil Dr. Abel Gilbert Pontón**.

Un grupo de pacientes en su stand comparten con los asistentes lo que hacemos como organización de pacientes con el apoyo de médicos y autoridades de esta casa de salud, donde nos reunimos mensualmente para tener charlas médicas educativas y compartir experiencias de paciente a paciente.

April 9 - World Health Day

For the World Health Day, FAETH was invited to the open house organized by the Hospital of Specialties Guayaquil Dr. Abel Gilbert Pontoon.

A group of patients in their stand share with the attendees what we do as an organization of patients with the support of doctors and authorities of this health house, where we meet monthly to have educational medical talks and share experiences from patient to patient.



Programa Ponte Bella

Pacientes con **Acromegalia** reciben sesión de maquillaje terapéutico con el afán de fortalecer su estado de ánimo y su autoestima.

Formando parte del programa Ponte Bella que el **Hospital de Especialidades Guayaquil Dr. Abel Gilbert Pontón** mantiene en esta casa de salud como apoyo terapéutico para sus pacientes.

Ponte Bella Program

Patients with acromegaly receive therapeutic makeup session with the desire to strengthen their mood and self-esteem.

Being part of the Ponte Bella program that the Hospital of Specialties Guayaquil Dr. Abel Gilbert Pontoon maintains in this house of health as therapeutic support for his patients.





Editorial activities | Content Summary - April-June 2019

In this summary we provide links to a few selected articles and podcasts. Please send us a note if you need additional information on sources and other resources.

Pituitary MRI educational video series

In March 2019 we began publishing a series of videos where Dr. Lewis Blevins, Pituitary World News co-founder and director of the pituitary center at the University of California San Francisco, illustrates different cases of pituitary tumors. There are 19 educational videos available with a range of fascinating cases. [You can see the videos here](#)

Podcasts and articles

Several interesting reviews and podcasts:

Review and comments on two recent papers on Cushing's disease. This interesting manuscript – BIOCHEMICAL CONTROL DURING LONG-TERM FOLLOW-UP OF 230 ADULT PATIENTS WITH CUSHING DISEASE: A MULTICENTER RETROSPECTIVE STUDY – reports the outcomes data of management of a large multicenter cohort of patients with Cushing's disease. The second article review highlights the complexities in the postoperative evaluation of patients with Cushing's disease and the determination as to whether a patient has recurrent or persistent disease after surgery. [Read more here](#)

In this podcasts [Dr. Kevin Yuen talks about Adult Hormone Deficiency with Dr. Blevins](#) Click on the link to listen to the podcast

[EndocrineWeb](#) the publication for the American Association of Clinical Endocrinologist featured PWN founders, Lewis Blevins MD and J D Faccinetti. The article focuses on teaming up to explore the challenges facing someone with acromegaly. [Read the article here.](#)

For a comprehensive list of the content available at Pituitary World News, [click here](#) and scroll down to LATEST ARTICLES.

WAPO member activities

J D Faccinetti, PWN Chairman and co-founder, was nominated for a three-year term to the WAPO board. We are delighted to be a part of WAPO and look forward to many shared collaborations and programs.

We already published activities from WAPO member organizations in Spain, Ireland, the UK, Argentina, Chile, and Ecuador. We encourage all member to send us their actions and press releases for publishing.

Editorial and content Initiatives under development:

- We are presently working on several initiatives and articles related to the development of new drugs and other important subjects of importance to people and healthcare professionals dealing with pituitary disease.
- The PWN language editions, although slightly delayed due to technical challenges are still under development and slated to be launched soon with the Spanish edition “Pituitary World News en Español. We are very excited about this program. Stay tuned for more updates.

Please visit the WAPO - Pituitary World News joint section “NEWS FROM AROUND THE WORLD” [here...](#)

There are over 450 articles and podcasts available for reprint and translation at www.pituitaryworldnews.org – please contact us for more information.

Comments and replies to:

J D Faccinetti (Chairman, CEO)

jdfaccinetti@pituitarworldnews.com



INTERNATIONAL ACROMEGALY CONFERENCE – MARCH 20-22,2019 IN NEW ORLEANS

Jill Sisco from Acromegaly Community invited members of the WAPO Board to attend the conference.

Attendants WAPO:

Sue Kozij	Invited by Jill Sisco with a general WAPO Board invitation sponsored by Acromegaly Community
Sandra Mesri	Invited by Jill Sisco with a general WAPO Board invitation sponsored by Chiasma with an 'Educational Grant'
Muriël Marks	Invited by Jill Sisco with a general WAPO Board invitation sponsored by Chiasma with an 'Educational Grant'

Approx. 215 patients attended the Acromegaly Conference. The first two days were especially educational for patients. The meeting is organized every 2 years.

The joint part at the Pituitary Society was open for 2 hours for patients, physicians and nurses. It was very unique to join the moment a patient (Jill Sisco) and nurse advocate (Daphne Adelman) were invited to speak on Acromegaly. In all earlier meetings, only physicians were allowed to join!

The meeting rooms at the Drury Inn were fabulous. You could “feel” the rapport between Jill and her acromegaly members/friends during the entire event. A wonderful tribute was made to those who had been lost during the year either to physical illness or mental illness.

The presenters spoke on very relevant subjects specific to the pituitary patient.

Pain Management:

People who go to a pain management consultant do very well; Pain changes the way you see yourself – which causes anxiety as well; Although in remission, Acromegaly patients still have a lot of pain → Effects of operations still exist. 'A BODY NEVER FORGETS SURGERY'. Various options for pain management were discussed.

Depression and Self Care:

Depression affects 1-5 women, 1-10 men. Personal security is disrupted; How will this affect my relationships?; Keep that fighting spirit and positive attitude; Play an active role in your recovery and challenges; Alone time is important to recharge; Visualization when stressed and in pain helps a lot (e.g. go back in your mind to the beach, go back to another fun location); Do not accept but adopt - 'BE WHERE YOUR FEET ARE IN THE PRESENT MOMENT!' - 'Feel → Thoughts → Behaviour'

Neurosurgery:

Very good visuals of the operation; Tumor grows upwards with Asian people instead of downwards in other people; People who have had surgery a very long time ago and still have active disease should consider another operation, as advanced knowledge has been gained.

WAPO SUMMIT 2019 – LYON, FRANCE

The annual WAPO Summit 2019 was held from May 17-19 in Lyon, France. No coincidence the ECE2019 was held here too, since we collaborated on the Saturday afternoon at the European Society of Endocrinology Pre-Nurses Meeting.

The WAPO program started on Friday at 2pm. Many patient advocates renewed their contacts, many hugs and kisses and we met with several new patient advocates!

The program started with the best practices by several WAPO member organizations, followed by an impressive presentation by Karen Powell of the French Cancer Support – Languedoc. Karen spoke about her experiences and the way how patient volunteers can support other patients, but need to prevent to take all these stories to their own life and how to prevent this. She gave great insight in the importance not to 'fill in' on behalf of the other person, but just give supportive questions and ideas to help the patient in the right direction!

At the Welcome dinner with patient advocates, speakers and industry representatives, also several ESE representatives joined and mixed with the WAPO member organizations.

On Saturday, the program started early with a presentation by Kathy Redmond (Redmond Consulting) and Rachel Jones (Swii..ch). Both presentations shared a lot of practical information, to support the patient advocacies with their activities.

At 11:30 we all took the bus to the ECE2019 venue! After collecting ECE badges, we got a lunch box at the conference room and not later, the presentations started. Sandra Mesri shared information on the 'Mapping Project' and Muriël Marks presented on the 'experiences of a patient with secondary adrenal insufficiency'. The speakers were very informative and many patient advocates were blown away by the information shared!!

Sadly one of the WAPO Patient Advocates had to leave the meeting and visited a hospital for a check and support, but he could leave later at the same day.

The WAPO representatives left ECE at 16:45 by bus with a great experience and many new contacts.

On Sunday the results of the WAPO Poster contest were shared, and Raquel and Begoña (Spain) won the first price with their poster, and Vivian (Taiwan) won the 2nd price.

After this, the WAPO Annual General Meeting started and great discussions were held in the discussion round. New plans, ideas and suggestions to work on in 2019-2020.

All patient advocates joined the lunch and went their own way again

Muriël Marks – June 2019

FEATURE ARTICLE

THE ENDOCRINE SYSTEM AND EXERCISE

Hayley Darke, BExPhys (clin) / ESSAM / AEP



The endocrine system makes up part of our bodies internal communication and is made up of the hormone producers: the pituitary gland, thyroid gland, parathyroid gland, thymus, adrenal glands, pancreas, testes, and the ovaries. Environmental influences play a huge role in determining how these parts function and it needs, much like a successful business, an efficient communication system. If one team member is out of line there can be a destructive flow on effect. It is an integral system that works with all our other body systems to provide a barrier to environmental influences (Saladin, 2001).

Each day we are exposed to many influences that place stress on our systems. In comparison to the Nervous system which acts with speed, the Endocrine system is slow acting and can continue responding long after a stimulus stops. These “reactions” have widespread effects on the body and across different stages of our lives. For example, Growth hormone aiding bone, cartilage, and muscle growth in our younger years, to the ongoing remodeling and thickening of bone into adulthood (Saladin, 2001).

Regulation of hormones involves communication from organs as well as from glands. “Feedback loops” involving released hormones are key for regulating homeostasis, but disruption (from influences) can lead to excessive or inadequate levels. There are a range of Endocrine disorders which can come from the variations in hormone levels. These imbalances, and the ongoing responses, are influenced by different aspects of our lives including:

- Nutrition
- Physical activity
- Mental health and stress
- Sleep
- Ageing
- Smoking status

Imbalance disorders can be categorized as either Hypo-secretion (inadequate release of a hormone) or Hyper- secretion (excessive release of a hormone).

These include:

- *Hypo-secretion disorders*
 - Diabetes insipidus (Antidiuretic hormone)
 - Hypothyroidism (congenital – Thyroid hormone)
 - Pituitary dwarfism (Growth hormone)
 - Diabetes Mellitus (Insulin)
- *Hyper-secretion disorders*
 - Acromegaly, gigantism (growth hormone)
 - Hyperparathyroidism (PTH)
 - Cushing’s syndrome (cortisol), ACTH)
 - Adrenogenital syndrome (adrenal androgens)

Benefits of Physical Activity

Although there is limited research behind the effects of physical activity on hormone secretions and changes, there is a vast knowledge on the effects of exercise on the body and the positive influence it has on all its systems.

All physical activity including aerobic and resistance training is proven to have benefits for musculoskeletal conditions including mechanical, from systemic diseases, as well as non-specific musculoskeletal pain syndromes (Cameron, Selig, & Hemphill, 2011).

Exercise can:

- Increase your bone mineral density
- Maintain and improve joint ranges of motion, for those suffering arthritides or joint other joint problems.
- Build a higher pain tolerance leading to greater quality of life overall

With our cardiovascular system there is ongoing evidence of the beneficial effects of exercise on diseases and is effective for both primary and secondary prevention and rehabilitation (Cameron, Selig, & Hemphill, 2011). In the developed world, cardiovascular disease is a leading cause of morbidity and mortality. Major risk factors for cardiovascular disease include, metabolic (obesity, insulin resistance, type 2 diabetes mellitus, and dyslipidaemias), cardiovascular (high blood pressure, auto-immune and inflammatory over-activity), and/or behavioral (poor nutrition, physical activity level, poor sleep hygiene, smoking status, stress).

The most significant risk factor, next to smoking, is living a sedentary lifestyle and it is now a major marker for predicting cardiovascular morbidity and mortality (Cameron, Selig, & Hemphill, 2011). Exercise and increased activity can lower blood pressure, improve heart rate and overall fitness level, improve cholesterol levels, improve the sympathetic nervous response, as well as improve the peripheral arterial system.

When it comes to metabolic disorders exercise is a multifaceted prescription and has been shown to be just as effective as pharmacotherapy. Obesity, metabolic syndrome, polycystic ovary syndrome, and type 2 diabetes mellitus can all lead to cardiovascular disease and the treatment for all consists of changes to the behavioral factors, and pharmacological interventions (Cameron, Selig, & Hemphill, 2011). Even the smallest increases to physical activity levels can have vast impacts on an individual's mortality rate.

Pharmacotherapy vs Exercise therapy

A range of pharmacological options are prescribed for metabolic risk factors and diseases. Many of which, although having benefit, can come with a range of side effects. Appropriately prescribed, exercise can reduce the need for pharmacotherapy and it has no side-effects or long-term adverse effect.

Pharmacological treatment usually targets specific disorders/conditions, but exercise has a wide range of benefits for all body systems.

It can:

- Reduce your weight
- Improve your glucose metabolism and control
- Lower your HbA1c (2-3 monthly check of how well diabetes is controlled- percentage of haemoglobin that is bound to glucose)
- Improve your reproductive outcomes
- Have differential effects on resting and exercise-induced hormone production and release (McArdle, Katch, & Katch, 2014)
- Elevate β -endorphins and other opioid-like hormones that contribute to euphoria
- Have positive effects on immune function
- Improve stress control

As an Exercise Physiologist I see clients on a range of medications and we are educated on their effects and how best to work with, not against, the bodies processes. In my profession I have had a number of clients with poor hormone regulation and have seen how improving different aspects of the complex systems of our body can lead to overall changes of the endocrine system. And this does not have to mean major habitual changes, but it does mean a change in perspective when it comes to physical activity and exercise.

The main goal for change is not about thinking you have to move more; it's about sitting less and reducing levels of inactivity (i.e. sitting at the computer or watching TV).

Some easy tips for moving more at home:

- Swap stacking the dishwasher for doing the dishes in the sink
- Hang out your clothes instead of using the dryer
- Set a timer for every 2 hours if you know you have work to do sitting
- Walk the pets more (1m more than yesterday is closer to better health)
- Babysitting the grandkids (or any kids, my nephews sure tire me out!)
- Park further from your destination
- Taking the stairs when you can
- Doing groceries (no online ordering)

If you find exercise a daunting word, then these easy strategies are a good starting point. Anything above your current activity will have benefits on your health - 1 minute is better than 0 minutes to start. If you are looking for more, then booking in to see an appropriate allied health professional, like an Exercise Physiologist, is the way to go.

What is an Exercise Physiologist?

An Exercise Physiologist (or Accredited Exercise Physiologist) is a university qualified allied health professional equipped with the knowledge and skills to provide safe and effective exercise interventions for people with acute, sub-acute or chronic medical conditions, injuries or disabilities. Using evidence-based practice, we work with clients to improve quality of life and create long-term changes for ailments. We work with clients to improve self-management of conditions and so reduce the need for costly ongoing aid.

There is a strong understanding in our profession that individuals differ greatly, and when a client arrives with a specific issue, we look beyond to help the whole body. From guidance with posture, gait (walking pattern), and pain issues, to the cardiovascular issues mentioned earlier, an Exercise Physiologist can provide the right advice for steps forward.

If this sounds like a professional you or someone you know would benefit from seeing, book an appointment with an Exercise Physiologist!

References

McArdle, W.D., Katch, F. I. & Katch, V. L. (2014). *Exercise Physiology* (7th ed.) Philadelphia:Lippincott Williams and Williams.

Saladin, K. S. (2001). *Anatomy & Physiology* (5th ed.). McGraw-Hill

Cameron, M., Selig, S., & Hemphill, D. (2011). *Clinical Exercise: A case-based approach*. Sydney: Churchill Livingstone/Elsevier

PATIENT STORY

HOW AN EXERCISE PHYSIOLOGIST INSPIRED ME...

I've never been a person to exercise - ever since I was young. I used to play some sport, sure... but exercise?? My husband tried to be supportive and encouraged me to walk the streets with him, but of course this was rejected very fast with "The weather is too hot", "I'm too tired", "My foot is sore".

Through the experiences of polycystic ovaries, Cushing's Disease, heart attack and Type 2 diabetes – the thought of exercise still daunts me. I am not sure why. There is always Monday to start – it is the same with dieting....

I have had two experiences of being under the supervision of an Exercise Physiologist. The first was when I experienced a heart attack at the age of 55. After treatment in hospital I was placed into a rehabilitation class by the hospital (great follow-up by the way!). An Exercise Physiologist delivered tuition on the benefits of exercise, and the fact that it can assist to "remodel" your heart after a heart attack, to give you the best chance of a good recovery. Amazing isn't it??? Of course, other tuition was provided, dietary help, psychology etc... The class had a number of machines to use and we were closely monitored by a number of Exercise Physiologists. Our heart rate and sugar levels were taken before, during and after the sessions. It was again amazing how the sugar levels in the blood stream reduced over such a short period while I exercised.

My second experience was to join a program that the Government funds in Australia for those with Diabetes. (Yes, we are fortunate with our healthcare). This is where I met Hayley. Hayley was very attentive to my individual needs – i.e. past Cushing's disease which has left me with fatigue and also a very hot body – just to clarify.... not hot as in gorgeous and beautiful (I wish!) – but hot as in red faced, perspiration that gets out of control and my body feeling like it is micro-waiving from the inside. And then there is the issue of my vertebrae (ouch!).

We paced it through together. Hayley took my blood sugar levels before and after the carefully considered exercises she thought would benefit me most. Each session my weight was also taken, and she took the time to really listen to me. How can you explain to some-one who looks so fit, what it is like to have residual issues after pituitary disease? Not easy, but if that person has taken the time to be well educated around your health issues, it makes a great difference.

During my time at the program I found it so beneficial – it made me feel happy, and my body seemed to loosen up - but on some days I dragged myself there I will admit. It was the fatigue I think and all the perspiration. It really helped to know that this person was genuinely wanting to support me.

I am waiting for the hot weather here to settle down before I enter into another class with Hayley. I really need to get my act together, and it is an Exercise Physiologist that will stand beside me and encourage me.

Susan Kozij - May 2019

We encourage you to ask a clinician in your country to write an article of interest for the newsletter, please send to the [Editor](#).

THE RECYCLE HEALTH STORY

ONE PERSON'S TRASH IS ANOTHER'S TREASURE

RecycleHealth is a nonprofit that collects fitness trackers and provides them to underserved populations. Since 2015, we have collected more than 4,000 trackers, mostly Fitbits, and have donated them to different groups looking to improve people's health and fitness. I started RecycleHealth with the simple goal of collecting fitness trackers that people no longer use and providing them free to underserved populations who may not be able to afford them but may benefit from their use.

Despite being a regular tracker user myself, going through various models over the years, the idea for RecycleHealth can be traced back to one moment. While preparing for a lecture at Tufts University School of Medicine, where I am on the faculty, I read that the heaviest purchasers of trackers are 18- to 34-year-olds, who are also the healthiest segment of our adult population. Furthermore, one-third of people abandon their trackers within six months. This sparked an idea: I wondered if I could collect the trackers people are no longer using and give them to those who can't afford them but might benefit from their use. When I mentioned the idea to some of my students, their enthusiastic response gave me the impetus to start RecycleHealth. I found out quickly that my idea worked: many people were happy to send us their trackers for a good cause -- one that helps others while also reducing clutter and e-waste. Since our start, we have received trackers from every state in the U.S. and from countries all over the globe. We have also received donations from vendors, including Withings, Fitbit, and Fossil. The fact that we have received more than 4,000 astonishes me, but I know there are many more sitting in junk drawers just waiting to be sent to RecycleHealth. The other side of my idea was to provide the trackers to underserved populations, and we have more groups requesting trackers than we can supply.

We have provided trackers to lower income older adults, homeless populations, adults with intellectual disabilities, and veterans with PTSD. It is gratifying to hear the stories of those we are helping; recently I walked into a senior center and a recipient of one of our trackers gave me a hug and showed me that she had 1,000 steps and it was only 9 a.m.

While we're called RecycleHealth, we are actually focused on the idea of reusing, refurbishing, and redistributing. We clean and test the trackers people send us. For the trackers that are broken beyond repair, we take them apart, recycle the components properly so they don't end up in a landfill and make earrings out of the circuit boards. My mother-in-law wears a pair and gets many compliments!

What's next for RecycleHealth

We're exploring exciting new areas. One I am particularly passionate about is learning more about the impact of poor digital literacy skills on older adults' adoption and use of digital health. This interest arose from working with older adults in senior centers to help them overcome the challenge of setting up trackers and apps. Another idea we're exploring is in developing displays of tracker data that physicians can use to provide patients with more tailored counseling about physical activity. A physician colleague of mine and RecycleHealth's Wellness Leader, Dr. Jeff Phillips, has lent his expertise and passion to this idea and others. Our main goal is to get more trackers out of people's junk drawers and onto more people's wrists. As such we are excited to be working with WAPO and providing participants with trackers and hope they are useful. We

would love to hear from WAPO participants to hear how you find it helpful to use a tracker! Please send a story and photo to lisa.gualtieri@tufts.edu

Assist Prof. Lisa Gualtieri, PhD, ScM

Dept. of Public Health & Community Medicine, Tufts University School of Medicine.

WAPO is so thankful to Lisa Gualtieri for donating 50 Health Trackers for participants to wear at the 2019 Summit and to also take home for continued use! All patient participants (and some guests and speakers!) wore the health trackers during the duration of the event. On conclusion we asked for their opinions and how they felt whilst using it.

Number of trackers: 45 trackers were handed out

Number of steps over a 3-day period: between 18,000 – 36,500 in 3 days

Comments by participants were overall very positive, e.g. “Pleasant to wear”, “Novelty”, “Will follow-up in my own country”, “Will write about this in our Newsletter to promote the activity”, etc. Some health trackers couldn’t be started, but these were replaced.

The WAPO Board congratulates Recycle Health on this fantastic initiative and research!

WALKING QUOTES

- After a day's walk everything has twice its usual value. (George Macauley Trevelyan)
- The best remedy for a short temper is a long walk. (Jacqueline Schiff)
- An early-morning walk is a blessing for the whole day. (Henry David Thoreau)
- Everywhere is walking distance if you have the time.
- If you are seeking creative ideas, go out walking. Angels whisper to a man when he goes for a walk. (Raymond Inmon)
- In every walk with nature one receives far more than he seeks. (John Muir)
- Me thinks that the moment my legs begin to move, my thoughts begin to flow. (Henry David Thoreau)
- A pedestrian is a man in danger of his life. A walker is a man in possession of his soul. (David Mccord)
- Perhaps the truth depends on a walk around the lake. (Wallace Stevens)
- There is nothing like walking to get the feel of a country. A fine landscape is like a piece of music; it must be taken at the right tempo. Even a bicycle goes too fast. (Paul Scott Mowrer)
- Thoughts come clearly while one walks. (Thomas Mann)
- A vigorous five-mile walk will do more good for an unhappy but otherwise healthy adult than all the medicine and psychology in the world. (Paul Dudley White)
- Walking is the great adventure, the first meditation, a practice of heartiness and soul primary to humankind. Walking is the exact balance between spirit and humility. (Gary Snyder)
- Walks. The body advances, while the mind flutters around it like a bird. (Jules Renard)
- Lack of activity destroys the good condition of every human being, while movement and methodical physical exercise save it and preserve it. (Plato)
- Movement is a medicine for creating change in a person's physical, emotional, and mental states. (Carol Welch)

Thank you Jill!

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 Editor@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 the below globally and locally:

- Events and conferences with sessions or context related to pituitary conditions
- Pituitary related awareness days
- Other related awareness days

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

July 2019

14 TO 17 July – [The Magic Foundation 25th Annual Convention](#), West Yorktown, Lombard, Illinois, USA

22 to 24 July – [Orphan Drugs & Rare Diseases Global Congress 2019 Americas](#) – West Coast San Francisco, USA

September 2019

10 to 11 September – [World Drug Safety Congress](#), Amsterdam, Netherlands (WAPO will be present)

27 to 29 September – [National Acromegaly Conference](#), Toronto, Canada



SOCIAL MEDIA

All full members of WAPO participate in our exclusive Facebook WAPO forum. This is a confidential area where members of WAPO can share their information and questions – in an informal setting – to gain new information, discuss issues and share projects.

We respectfully request that if members wish to use any information contained within this forum that you personally contact the other party for permission.

Procedure: Please email mail@wapo.org for the link to join.



NEWS

In this section, we will share interesting or important information of organizations, to which WAPO is related, received via their newsletters.

IAPO Newsletter:

'World Patient Safety Day adopted by 72nd World Health Assembly'

IAPO is extremely delighted that on Friday 24th May 2019 the World Health Organization (WHO) Member States from all 194 countries endorsed the establishment of a World Patient Safety Day to be marked annually on **17 September** and officially including it on WHO list of health dates. Would you to read more? [Click here](#).

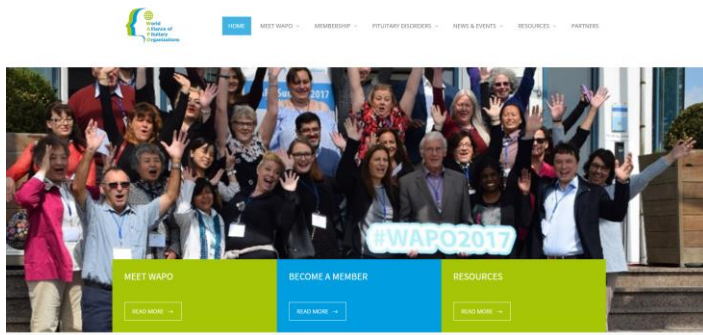


GOTTA KEEP IT LIGHT!

Quotes

- Aerobics: a series of strenuous exercises which help convert fats, sugars into aches, pains and cramps.
- Exercise: you don't have time not to.
- Exercise is a dirty word. Every time I hear it, I wash my mouth out with chocolate.
- Fifty years ago people finished a day's work and needed rest. Today they need exercise.
- The first time I see a jogger smiling, I'll consider it. (Quote Joan Rivers, on when she will start jogging)
- I don't jog. It makes the ice jump right out of my glass.
- I had to give up jogging for my health. My thighs kept rubbing together and setting my pantyhose on fire.
- I have to exercise early in the morning before my brain figures out what I am doing. (Quote Marsha Doble)
- If God wanted me to touch my toes, he would have put them on my knees.
- If it wasn't for my superior willpower, I might be exercising right now!
- I'm not into working out. My philosophy: No pain, no pain. (Quote Carol Leifer)
- My idea of exercise is a good brisk sit. (Quote Phyllis Diller)
- The trouble with jogging is that by the time you realize you're not in shape for it, it's too far to walk back. (Quote Franklin Jones)





Screenshot from the WAPO Website – www.wapo.org

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Twitter: WAPO_org

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Can everyone please *like* or *share* our Facebook page to give WAPO some more exposure. Please, if you have information to share, let us know and we will put it up for you.

WEBSITE

www.wapo.org Please keep checking the WAPO website, which we are changing regularly.

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.

WAPO does not engage in the practice of medicine, endorse any commercial products, doctors, surgeons, medications, treatment, or techniques. The opinions expressed in this newsletter are those of the individual author, and do not necessarily reflect the views of individual officers, doctors, members, or health care providers. The content of patient's stories are the opinion of individuals and not the World Alliance of Pituitary Organizations or its office bearers.

You should not rely on information contained in this newsletter to make decisions about your health or lifestyle without consulting a health professional. WAPO does not accept liability for any injury, loss or damage incurred by use of or reliance on information in this newsletter.
