

THE GLOBAL PITUITARY VOICE

JOURNAL FROM WAPO

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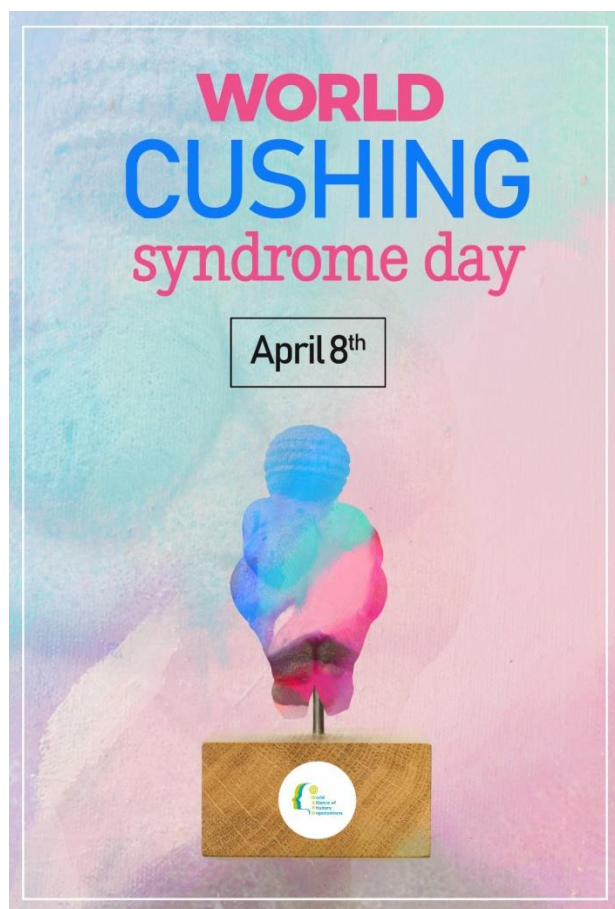


OUR VISION

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.



RARE DISEASE DAY 2020
29 FEBRUARY

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CHAIR'S REPORT

Dear WAPO members and friends,

Welcome to the first issue of The Global Pituitary Voice in 2020.



This newsletter is being released in between two important dates for the pituitary community, just a few days after the Rare Disease Day and a few days before the proposed 5th WAPO Summit. Both dates had their impact on the issue's content.

The Rare Disease Day is an opportunity for us to join our voice to this of all other rare disease patients and raise awareness about the conditions our community represents and the problems we face. In the newsletter, you will see examples of events and actions run by some WAPO members around the 29th of February, the Rare Disease Day. More news from our members on that day are at WAPO [Facebook page](#).

As you all know, the Anniversary 5th Summit in Buenos Aires, has been postponed till October 2-4 instead of March 2020. We hope that COVID-19 virus will have overpassed by that time and will not stop us from running the Summit. We are keeping the very rich program as currently planned and hope it will be as useful for WAPO members as it has been for the past years. See [page 18](#) for more details and please come.

We plan to run a training for endocrine nurses at the Summit. Understanding the role of nurses for the pituitary patient's quality of life, we have also made the nurses this newsletter's protagonists.

The WAPO Board is working hard in order to get ready for the Summit, and we look forward to seeing patient advocates in Argentina in person and get news from those who can't.

Don't forget about the Cushing's Awareness Day on the 8th of April. WAPO will run a global awareness campaign on that date, please join the campaign and share the visual materials via your social networks!

Please enjoy reading the Global Pituitary Voice, and share it in social media and directly with your members, colleagues, partners, volunteers, friends and all those who care.

Best wishes,

Andrei Andrusov
WAPO Chair

A blue ink signature of Andrei Andrusov, written over the printed name.

Rare Diseases Day –
Rome, ITALY



Year of the Nurse



Rare Diseases Day –
Perth, AUS

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

Pituitary World News



WORLD

This is a summary of the latest articles and opinions published by Pituitary World News. If you would like additional resources or more background from any of the materials published, please contact us at info@pituitaryworldnews.com – you can also get more information on published content by accessing our social media feeds. <https://www.facebook.com/pituitaryworldnews/>

<https://twitter.com/PituitaryWNNews>

NOTE FROM PWN EDITORS:

The WAPO – PWN joint section in the Pituitary World News section called “NEWS FROM AROUND THE WORLD” is designed, among other things, to promote WAPO member organization initiatives and encourage the sharing of best practices. Please contact us to share any information, opinions, or articles you feel might benefit the global pituitary community.

Podcasts:

We focused most of our attention on the activities surrounding the development of new drugs and therapies for pituitary disease. We published 5 podcasts of a series titled “the journey to a new drug. You can hear these podcasts accessing the links below

- [Exploration, Innovation and Creativity: An intimate look at new drug development in the world of pituitary and neuroendocrine disease](#) - This is the first in a series of 6 podcasts on the ins and outs of drug development. In it, we discuss the journey that a promising molecule takes to develop into a life-saving medication and the people that steer that rigorous work. How does a company go from a molecule to the actual medication? What are the steps? Who is involved? What are the processes and barriers? And what does that process look like in real-time? Thanks to a kind invitation from Dr. Scott Struthers, chairman of Crinetics Pharmaceutical and his team, PWN readers and listeners will get an unfettered look at a young company's efforts to develop new drugs to solve unmet needs in acromegaly, Cushing's and rare neuroendocrine disease
- [The business and commercial considerations of new drug development](#) - The second podcast in [our continuing series on drug development](#) focuses on the commercial and business aspects of getting a growing company ready for a new drug. Today we talk with Gina Ford, [Crinetics](#)' Vice president of Corporate Strategy and Commercial Planning, about the challenges and opportunities as these new potential medications move through the development pipeline.

- [Giving patients a place at the table](#) - The third podcast in our series on drug development touches on the effort that industry is making to partner with patients to understand needs, preferences, and attitudes, and to develop insights that would result in better drugs and therapeutic experiences. In our conversation with Stephanie Kallay, Crinetics Director of Patient Advocacy, we discuss their effort to, as Stephanie put it, give the patient a place at the table. We talked about listening to the voice of the patient, the opportunities and challenges of engaging patients and the efforts that the industry is making to include their perspectives in everything they do.
- [Podcast series “the journey to a new drug”: understanding molecules and receptors](#) - this podcast, the fourth in our drug development series “the journey to a new drug,” brings you my conversation with Dr. Stephen Betz, cofounder at crinetics pharmaceutical. Our discussion spotlights new drugs for acromegaly, Cushing’s, and pediatric hyperinsulinism, currently under development at crinetics. It includes a fascinating talk on molecules and how they work with cell receptors to eventually provide a launching pad for new drugs. We hope this podcast will serve up a better understanding of the many steps required to find and bring new medications and therapies to patients.
- [The fascinating work of discovering a new molecule](#) - Today we continue our series on new drug development – “the journey to a new drug.” This is a captivating conversation with Dr. Stacy Markison – who is Crinetics senior director of Pharmacology and Toxicology – about the science of discovery and the work that goes into making sure a compound is safe for human studies and does what it’s supposed to do.
- [Tackling unmet needs: new compounds in development for non-functioning pituitary adenomas and rare endocrine diseases](#). In this podcast, we highlight a new company dedicated to the rare endocrine disease world. [Tiburio Therapeutics](#) is working on [two exciting compounds](#) for the treatment of [Non-functioning Pituitary Adenomas](#) and rare endocrine disorders. Dr. Blevins and I caught up with [Abe Ceesay, Tiburio CEO and Nerissa Kreher M.D., Chief Medical Officer](#), both highly experienced professionals in the rare endocrine space. We had a fascinating talk about their plans in this area of extensive need for patients. Here’s our talk.

[Read more here](#) about all of the podcasts available to share. And for a comprehensive list of the content available at Pituitary World News, [click here](#) and scroll down to LATEST ARTICLES.

Pituitary MRI educational video series:

The MRI educational series continues with more MRI cases in which 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. [You can see the videos here](#)

Other activities:

In January we also highlighted several patient videos published by the [Cushing's Support and Research Foundation](#) (CSRF)

The US based patient support group Acromegaly Community is hosting an important meeting with the Food And Drug Administration a US federal agency responsible for protecting and promoting [public health](#) through the control and supervision of drug development among many other activities. In 2012 the US Food and Drug Administration began conducting the Patient-Focused Drug Development initiative to gain more understanding of the patient perspective on specific diseases and the available treatments. Read more [here](#) and [here](#) about this upcoming meeting.

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

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

J D Faccinetti, March 2020



PEOPLE'S REPUBLIC OF CHINA

February 29th was International Rare Disease Day. Every year on this day, the Illness Challenge Foundation (ICF) from China calls upon everyone to pay attention to and support the patients and families affected by rare diseases.

The theme of this year's Rare Disease Day was “We Are the 300 Million”. According to a recent research, there are around 300 million people globally who are affected by rare diseases.¹ After discussing with rare disease patient organizations in China, we transformed the slogan into “300 million worldwide, Never rare (300 Million Worldwide, Never Rare)” (“全球三亿，从不罕见” in Chinese). With this slogan, we hope the voices of the rare disease community can be heard all around the world.

Since January 2020, China has been seriously hit by the COVID-19 outbreak. Healthcare professionals across the country are racing against time to save lives. Friends from all over the world have also lent a helping hand to people in China. At this crucial moment, the ICF proposed an initiative to all rare disease organizations and patient groups around the world, calling on everyone – patients, families, and friends – to take part in the “300 Million Thanks” campaign by sending out a note of gratitude and support to all healthcare professionals on the frontlines.

The strongest bonds that rare disease patients have, besides the ones with their families and friends, are the ones with healthcare professionals. Many people had a moving experience when they sought medical treatment, and many patients have formed deep friendships with their doctors. So, we call on our patients to say to all medical staff through texts, videos, etc. Thank you to all the doctors, nurses, and medical staff who have helped me. Thank you to everyone on the frontlines who are fighting this epidemic.

After the initiative was issued, we received positive responses from the majority of rare disease organizations and groups in China, and they were eager to launch this campaign together. We invited foreign rare disease organizations to join us as “co-sponsors” so that we can collectively mobilize patients and the media to spread the word. (Attach specific participation methods.)

Healthcare practitioners deserve to be treated with care, too. So, this time we were not asking others to pay attention to the needs of rare disease patients, but to bring together the strength of 300 million rare disease patients worldwide, carrying our wish through “300 million thanks” to make healthcare workers feel the “rare” warmth and love. We want everyone to see that people with rare diseases are not defeated by their pain. Instead, we all look forward to pass on our love to those who are currently fighting for us and others.

Note 1: Wakap SN, Lambert DM, Olry A, Rodwell C, Gueydan C, Lanneau V, Murphy D, Le Cam Y, Rath A. Estimating cumulative point prevalence of rare diseases: analysis of the Orphanet database. *European Journal of Human Genetics*. 2020 Feb; 28 (2): 165-73.

We invited friends with rare diseases from all over the world to participate with us. Using their smartphone, recording a short (30 seconds max) video without any filters, special effects, or subtitles. We shared the videos on social media platforms in China - [Facebook](#) and [Twitter](#) using the hashtags #300millionthanks & #rarediseaseday.

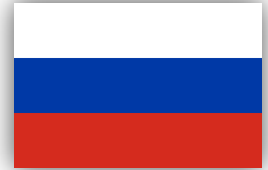
What is ICF?

The Beijing Illness Challenge Foundation (ICF) is the very first public welfare foundation in Beijing focusing on the field of rare diseases. ICF is devoted to solving urgent matters faced by the rare disease community through community services, non-profit sector development, social advocacy, and eventually creating an equal and respectful environment for the community challenged by illness in the society. The Foundation is inspired by “the Ice Bucket Challenge” and founded on 29th February 2016, the International Rare Disease Day.

基金会介绍 (What is ICF)

北京病痛挑战公益基金会（简称病痛挑战基金会，英文缩写 ICF）是北京市第一家关注罕见病领域的公益基金会，致力于通过社群服务、行业发展、社会倡导，共同解决罕见病群体面临的迫切问题，为面临病痛挑战的人士，建立平等、受尊重的社会环境。本基金缘起于“冰桶挑战”，于 2016 年 2 月 29 日国际罕见病日正式宣告成立





RUSSIA

Promoting the information via the Internet is one of the main objectives for every modern organization or company.

This is especially true for organizations which goal is to raise awareness about rare diseases. Patients search for information about their rare illness on a wide variety of sometimes proven, but also often unverified resources. They try to compile the whole picture of the disease, and treatment, and surgery, and how to live in the future with such a severe diagnosis as acromegaly.

And those who did not find reliable information?! Those who believed dubious resources... what about them?

In order to reach the goal of raising awareness, the patient organization "Velikan" from St. Petersburg is actively developing its Internet resources. During the second half of 2019, the website of "Velikan" was visited by more than 3,500 visitors. Video content posted on the YouTube channel was viewed 1623 times. By the December 31, the number of participants in the "vkontakte" social network group exceeded 600 people, and more than 400 patients visit the group monthly. Advertising companies have been created and maintained in the Google contextual advertising network.



The website is aligned with the requirements of the main fundraising platforms in Russia that support Non-profit organizations: Sberbank.Vmeste, Blago.ru, Takie dela, dobro@mail.ru, which will allow "Velikan" to attract additional resources to help its patients.

Now the patient organization is faced with the task of bringing the website in line with the new requirements of the rapidly developing digital environment. Velikan has recently launched a project to raise funds with the help of the leading crowdfunding platform in Russia "Planeta".

The website contains a video about the Velikan organization and about a "big man" who helps us in our work, Nikolay Valuev, the State Duma Deputy.

Link to YouTube will be a little later.

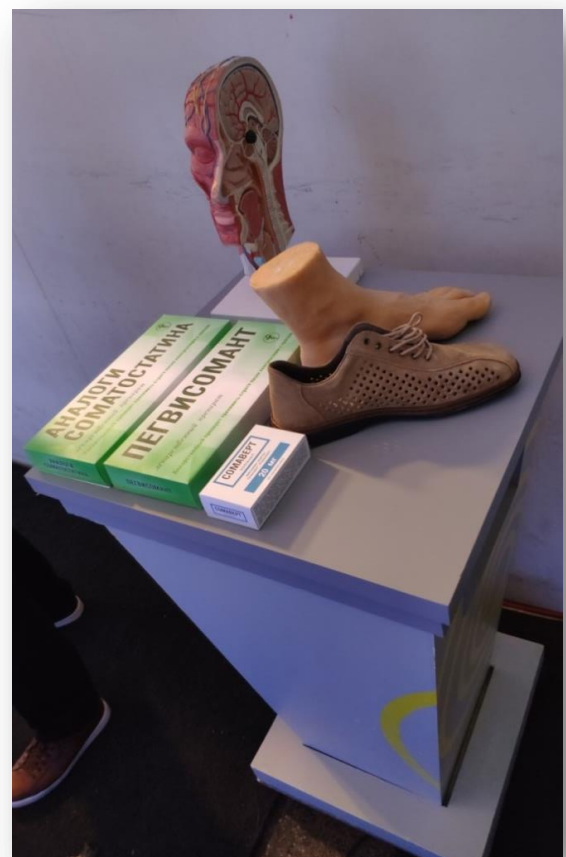
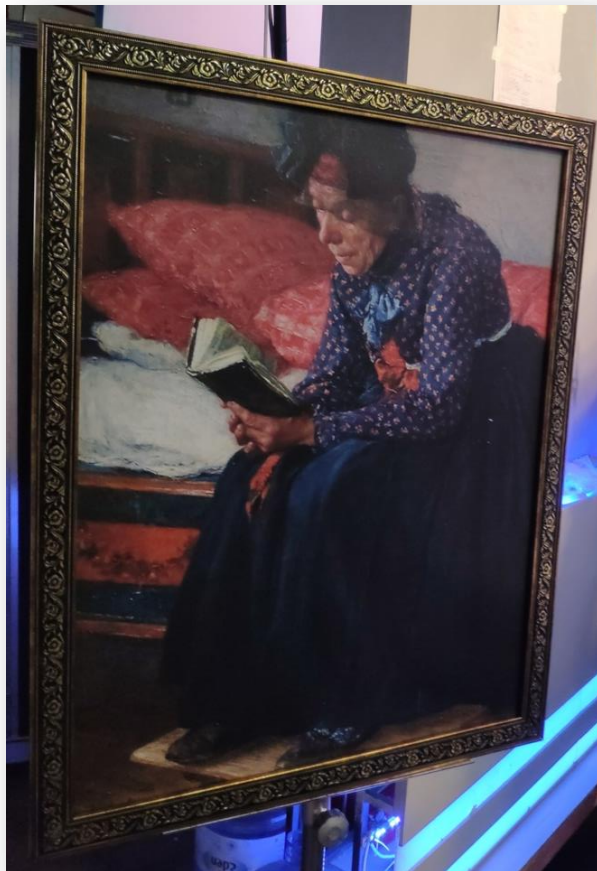
The video will be with subtitles.



On the 1st of November, the World Acromegaly Day on Russian main country #1 television channel, in the most famous health program “Live Healthy”, there was shown a story about acromegaly called “The Clinical Picture”.

The story is based on the art works of famous artists who captured people with rare diseases on their canvases. (a photo) Elena Malysheva spoke in great detail about the specificity of the disease and the Russian organization Velikan (means “giant”) was represented by the real giant Konstantin Pepelyaev whose height is 2 meters 20 cm.

Also, along by the main story they mentioned that the Velikan organization helps people with such a complex diagnosis!



Ekaterina Andrusova, February 2020



UNITED KINGDOM

December was a quieter month for our Charity - a time for us to take stock on what we want to achieve in 2020. In terms of funding however, we sold 5,500 Christmas cards, raised £6,000 in the sale of raffle tickets, and our Christmas fundraising appeal raised £6,300.

In addition, the UK Company Jonas Trading Ltd made us their Charity of the Year in 2019, and over the course of the year raised and donated £22,000. We have recently been notified by the Welsh Company Ecolab that they have chosen us as their Charity of the Year, and will be holding monthly fundraising events.

We also have many fundraising challenges organised throughout the year, including:

- three mountain climbs- Snowdon (highest mountain in Wales) by day and a moonlight trek, and Ben Nevis (highest mountain in Scotland and UK)
- two abseils- from the cliffs above the Avon Gorge in Bristol, and the second from the ArcelorMittal Orbit structure at the Olympic park London
- the season starts with the London Landmarks Half Marathon on 29th March however, with £5,000 already pledged in sponsorship



In continued support of our patient community January 2020 saw us announce the date for our National Conference, which will be held in October in Manchester. As usual, we already have some of the UK's leading Endocrinologists and other health professionals signed up to deliver presentations and deliver workshops.

On Mon 20 Jan, we held an hour long Twitter Takeover with Prof Stephanie Baldeweg. This provided an opportunity for pituitary patients to ask their questions directly to an endocrine expert.

Stephanie managed to answer around 24 questions in the hour and we had nearly 14,000 Twitter impressions that day and we are extremely grateful to her for giving up her evening to run this session.

With all that's planned, we are looking forward to the year ahead.

Sammy Harbut, February 2020



AUSTRALIA

We are proud to announce that our patient education sessions in 2019 are now ready for viewing.

Link for the Sessions - [APF Patient Information Session - Sept 2019](#) - they are on a separate playlist forming part of our APF YouTube Channel which also includes other videos.

Link to the APF YouTube Channel to subscribe to further videos as they come - [Australian Pituitary Foundation Videos YouTube Channel](#)

We have also recently revised and uploaded a new series of Fact Sheets on our website

Links to [Fact Sheets](#)

- [Cushings](#)
- [Hypopituitarism](#)
- [Pituitary Tumours](#)
- [Prolactinoma](#)

Malini Raj, March 2020



ECUADOR

[Hospital De Especialidades Teodoro Maldonado Carbo.](#)

December 7, 2019 Guayaquil, Ecuador

Compartiendo una mañana de integración médicos y pacientes.

[#Deliciosochocolate.](#)

[#FAETEcuador](#)

[#MirameSoyAcromegalico](#)

Sharing a morning of medical and patient integration.

[#Deliciosochocolate.](#)

[#FAETEcuador](#)

[#MirameSoyAcromegalico](#)



En el Hospital de Especialidades Eugenio Espejo de la Ciudad de Quito, medicos, autoridades y pacientes con Acromegalia compartimos un agasajo por navidad.



En el Malecón 2000.

Hablando de Enfermedades RARAS en el Ecuador Dr. Angel Ortiz A (genetista), y Psicólogo Cl. Francisco Brito de la importancia del apoyo Psicológico a pacientes que la padecen y su familia.

#HaciendonosVisibles

#Enfermedadesraras

Talking about RARE Diseases in Ecuador Dr. Angel Ortiz A (geneticist), and Psychologist Cl. Francisco Brito of the importance of psychological support to patients suffering from it and their family.

#HaciendonosVisibles

#Enfermedadesraras



FAETH presente en la casa abierta por el día mundial de las Enfermedades RARAS, en el hospital Guayaquil Dr. Abel Gilbert Pontón, con la participación las diferentes especialidades que tratan enfermedades RARAS en esta casa de Salud.

#Acromegalia #Enfermedadeshipofisarias
#FAETHEcuador #WAPO #ALIBER

FAETH present at the Open House for World RARE Diseases Day, at Guayaquil Dr. Abel Gilbert Pontón, with the participation of the different specialties that treat rare diseases in this house of health.

#Acromegalia #Enfermedadeshipofisarias
#FAETHEcuador #WAPO #ALIBER



Margarita Vásquez Amoroso, March 2020



THE NETHERLANDS

‘New Members Day’

Annually the Bijnierverseniging NVACP (Dutch Adrenal Society NVACP) organizes a special day for new members and their caregivers, who have subscribed to a membership during the past year.

We organized this day on November 30, 2019 and 42 ‘New Members’ and several caregivers registered. It was very surprising when 49 members and 37 care givers arrived! Of course, we gave them all a great welcome!

The Bijnierverseniging NVACP focusses on several adrenal diseases, like Adrenalinsufficiency, Cushing’s Syndrome/Disease, CAH, Primary HyperAldosteronisme, Pheochromocytoma and Adrenal carcinoma for adults and youth.

People arrived between 12:00 - 13:00 pm and enjoyed a sandwich lunch including dietary wishes, since some of them had to travel for hours.

After a short welcome by Mrs. Karin van den Heuvel (Treasurer), Mrs. Alida Noordzij presented on all adrenal diseases, the Pituitary-Adrenal-axes, the importance of Cortisol levels, Hydrocortisone and the impact on our lives.

With a short break, everyone was ready to join a disease specific working group, which we created with 10 volunteers who are experienced in telephone support. These groups would sit in a separate room to discuss various topics. Recently we (re-) started a Caregiver working group, for which there is a great need!

During some of the discussion sessions, a lot of emotions came out. People recognized stories and experiences. The Caregiver group was especially emotional, because finally they could speak up freely with others about their feelings and the problems they meet. Sometimes it’s very hard to have a role as a caregiver. Help from other families or friends is very welcome.

Marijke Simon, February 2020

OBESITY IN CUSHINGS, NOT JUST OVER WEIGHT

Dr Debora Katz, Neuroendocrinología, Fleni, Center for Neurological Research, Argentina

Endogenous Cushing's syndrome (CS) is a rare disease due to a chronic cortisol excess. It affects predominantly women, with a female/male ratio ranges from 3 to 5ⁱ. Even if the cause of hypercortisolism may vary (being of pituitary, adrenal or ectopic origin), pituitary origin (also called Cushing's disease –CD) is the most common cause of endogenous CS, affecting approximately 70% of the patientsⁱⁱ.

Glucocorticoid excess in CS leads to complications such as increased visceral adipose tissue, obesity, impaired glucose tolerance, diabetes mellitus, hypertension, hyperlipidemia, osteoporosis, and neuropsychiatric comorbidities, and is associated with a significantly increased mortality.^{iii, iv, v, vi}

In patients with manifest comorbidities at diagnosis, remission of Cushing's syndrome resolved diabetes in 56% of cases, hypertension in 36% of cases, hyperlipidaemia in 23%, and depression in 52% of cases.^{vii}

Overweight and obesity are still prevalent at follow-up, also after remission from Cushing's disease and despite a noticeable decrease in nearly all fat depots and improvement of fat distribution.^{viii, ix} Ten years after remission from CS, patients still display persistent accumulation of central fat and an unfavorable adipokine profile, both contributing to a state of persistent low-grade inflammation and to an increased degree of atherosclerosis^x.

So, the cardiovascular risk profile improves after Cushing's remission, but does not normalize^{xi}. In patients with glucocorticoid-associated hyperglycemia, insulin-sensitizers, such as metformin and thiazolidinediones, are considered as first-line therapy. These can be combined with agents that increase post-prandial insulin secretion such as dipeptidyl peptidase 4 inhibitors (DDP4-Is), GLP-1 receptor agonists, sulfonylureas, or glinides. The effect of metformin (and potentially thiazolidinediones) on adipose tissue and other organ AMPK could be beneficial. GLP-1 analogues and DDP4- I may be helpful in the management of GC-induced diabetes, increasing glucosedependent insulin secretion and reducing glucagon secretion as well as having positive effects on β -cells, appetite, fat distribution, hyperlipidemia, heart, and bone. Metformin as first-line, and an incretin-based approach as second-line, have been suggested for the management of pasireotide related hyperglycemia. Treatment with insulin analogues can be considered when oral hypoglycemic agents are not effective.^{xii}

Cushing's syndrome patients show loss of muscle function that cannot be explained by loss of muscle mass. Impaired muscle quality due to fat infiltration may be the reason. This is supported by the observation that Cushing's syndrome patients with impaired glucose metabolism show strongest deterioration of muscle function.^{xiii}

Quality of life (QoL) is impaired in patients with hypercortisolism due to CS of any aetiology. It is worse in active disease, but improvement after successful therapy is often incomplete, due to persistent physical and psychological co-morbidities, even years after endocrine “cure”. Physical symptoms like extreme fatigability, central obesity with limb atrophy, hypertension, fractures, and different skin abnormalities severely impair the affected patients’ everyday life. Psychological and cognitive problems like bad memory, difficulties to concentrate and emotional distress, often associated with anxiety and depression, make it difficult for many patients to overcome the aftermath of treated Cushing’s syndrome. Recent studies have shown diffuse structural abnormalities in the central nervous system during active hypercortisolism, thought to be related to the wide distribution of glucocorticoid receptors throughout the brain. Even though they improve after treatment, normalization is often not complete.^{xiv} This finding highlights the importance of early diagnosis, but also the need to treat also in mild cases of CS.

Although the pharmacological control of hypercortisolism can improve the metabolic alterations and positively impact on cardiovascular changes, the glucocorticoid-associated metabolic comorbidities require prompt and appropriate management in order to reduce morbidity.

One should be aware that common complaints like cognitive impairments and psychiatric disorders, as well as periodic follow-ups to evaluate pituitary function and detect possible recurrences of hypercortisolism, all put extra stress on these CS patients, which in turn worsens psychological issues and often leads to a bad QoL.

Encouraging the patients to take care of themselves can help them feel better and improve their QoL, with the support of friends and family, so they can feel they are taking the reins of their lives again. Things to recommend are to consider taking up new hobbies or challenges within their capacities, as well as following healthy diets and regular exercise and taking their prescribed treatment as indicated.^{xv}

A specific nursing educational program, addressed to CS patients has been shown to exert a positive effect on different living habits and in parallel, improved QoL. They improved their physical activity, healthy lifestyle habits, adherence to therapy, sleep patterns and experienced a reduction in pain level and in the use of health resources, all influencing QoL positively. Those patients who improved most with this educational intervention were those with greatest impairment in their QoL^{xvi}, while if the patient was depressed, recovery of QoL was more difficult^{xv}.

QoL is severely affected in patients diagnosed with Cushing’ syndrome, and may not normalize despite successful treatment and endocrine “cure”. The reasons are multifactorial, including physical symptoms (including fatigability, abnormal body image due to central obesity and several skin problems, hypertension, etc.) and psychological complaints; additionally, morphological abnormalities in the central nervous system, reflect the glucocorticoid toxicity on the brain, presumably through the glucocorticoid receptors identified in different brain areas. Understanding and encouragement by the health care providers and in some cases psychological support can help patients through this difficult period with the hope of ultimate improvement.^{xv}

*“Probably no one understands Cushing’s syndrome like someone who
has lived with the disease”
- Gotch 1994^{xvii}*

- ⁱ Newell-Price J, Bertagna X, Grossman AB, Nieman LK. Cushing’s syndrome. *Lancet*. (2006) 367:1605–17
- ⁱⁱ Boscaro M, Barzon L, Fallo F, Sonino N. Cushing’s syndrome. *Lancet*. (2001) 357:783–91.
- ⁱⁱⁱ R. Pivonello, A.M. Isidori, M.C. De Martino, J. Newell-Price, B. M. Biller, A. Colao, Complications of Cushing’s syndrome: state of the art. *Lancet Diabetes Endocrinol*. 4, 611–629 (2016)
- ^{iv} A. Lacroix, R.A. Feelders, C.A. Stratakis, L.K. Nieman, Cushing’s syndrome. *Lancet* 386, 913–927 (2015)
- ^v J.K. Lambert, L. Goldberg, S. Fayngold, J. Kostadinov, K.D. Post, E.B. Geer, Predictors of mortality and long-term outcomes in treated Cushing’s disease: a study of 346 patients. *J. Clin. Endocrinol. Metab*. 98, 1022–1030 (2013)
- ^{vi} R.N. Clayton, P.W. Jones, R.C. Reulen, P.M. Stewart, Z.K. Hassan-Smith, G. Ntali, N. Karavitaki, O.M. Dekkers, A.M. Pereira, M. Bolland, I. Holdaway, J. Lindholm, Mortality in patients with Cushing’s disease more than 10 years after remission: a multicentre, multinational, retrospective cohort study. *Lancet Diabetes Endocrinol*. 4, 569–576 (2016)
- ^{vii} Scherthaner-Reiter MH, Siess C, Gessl A, Scheuba C, Wolfsberger S, Riss P, Knosp E, Luger A, Vila G. Factors predicting long-term comorbidities in patients with Cushing’s syndrome in remission. *Endocrine*. 2019 Apr;64(1):157–168.
- ^{viii} A. Faggiano, R. Pivonello, S. Spiezia, M.C. De Martino, M. Filippella, C. Di Somma, G. Lombardi, A. Colao, Cardiovascular risk factors and common carotid artery caliber and stiffness in patients with Cushing’s disease during active disease and 1 year after disease remission. *J. Clin. Endocrinol. Metab*. 88, 2527–2533 (2003)
- ^{ix} E.B. Geer, W. Shen, E. Strohmayr, K.D. Post, P.U. Freda, Body composition and cardiovascular risk markers after remission of Cushing’s disease: a prospective study using whole-body MRI. *J. Clin. Endocrinol. Metab*. 97, 1702–1711 (2012)
- ^x M.J. Barahona, N. Sucunza, E. Resmini, J.M. Fernandez-Real, W. Ricart, J.M. Moreno-Navarrete, T. Puig, J. Farrerons, S.M. Webb, Persistent body fat mass and inflammatory marker increases after long-term cure of Cushing’s syndrome. *J. Clin. Endocrinol. Metab*. 94, 3365–3371 (2009)
- ^{xi} . A. Colao, R. Pivonello, S. Spiezia, A. Faggiano, D. Ferone, M. Filippella, P. Marzullo, G. Cerbone, M. Siciliani, G. Lombardi, Persistence of increased cardiovascular risk in patients with Cushing’s disease after five years of successful cure. *J. Clin. Endocrinol. Metab*. 84, 2664–2672 (1999)
- ^{xii} Ferraù F, Korbonits M. Metabolic Syndrome in Cushing’s Syndrome Patients. *Front Horm Res*. 2018;49:85–103.
- ^{xiii} Drey M, Berr CM, Reincke M, et al. Cushing’s syndrome: a model for sarcopenic obesity. *Endocrine*. 2017;57(3):481–485.
- ^{xiv} J Webb SM, Crespo I, Santos A, Resmini E, Aulinas A, Valassi E. Quality of life tools for the management of pituitary disease. *Eur J Endocrinol* 2017;177:R13–26.
- ^{xv} Dorn LD, Burgess ES, Friedman TC, Dubbert B, Gold PW, Chrousos GP. The longitudinal course of psychopathology in Cushing’s syndrome after correction of hypercortisolism. *J Clin Endocrinol Metab* 1997;82:912–9.
- ^{xvi} Martínez-Momblán MA, Gómez C, Santos A, Porta N, Esteve J, Úbeda I, et al. A specific nursing educational program in patients with Cushing’s syndrome. *Endocrine* 2016;53:199–209.
- ^{xvii} Gotch PM. Cushing’s syndrome from the patient’s perspective. *Endocrinol Metab Clin North Am*. 1994;23(3):607–617.

AWARENESS INITIATIVES

Summit 2020



This year we are celebrating a very important milestone for WAPO. The 5th Annual Summit!

Thank you to the following sponsors to make this possible:

Platinum: Pfizer

Gold: Ipsen, Novartis

Silver: HRA Rare Diseases, Strongbridge Bio

Bronze: Crinetics



The Summit was to be hosted in Buenos Aires, Argentina, 20th – 22nd March, 2020. All delegates have now been informed of a date shift to 2nd – 4th October this year. This is to append to the ISE (International Society of Endocrinology) Conference held at the same time in Argentina. More details to come later.

2020 is also “International Year of the Nurse”, therefore we have invited up to 20 Latin America Nurses to attend.

We have introduced the ‘Nurses Project’, to improve support to pituitary and adrenal patients by nurses (emergency instruction, information, etc.) which is common use in various areas such as Europe, Asia and USA, but **NOT** in LatAm. On the Sunday we have prepared a special day of training for the nurses, on how to support and patient, but demonstrate how nurses work well with Endocrine Health Professionals to enhance the quality of care of the patient.

We are pleased to be able to fund their attendance through grants from:

Pfizer

Crinetics

Great News! Most of the speakers have indicated they will be available on the new dates – so the program will remain mostly unchanged.

Friday, October 2:

Welcome & Introduction to WAPO members and guests

Best practices regarding 'Regional problems and possible solutions'

WAPO Mapping Project update.

Saturday, October 3:

Numerous presentations from leading specialists ranging from Growth hormone replacement in Acromegaly & Cushing's, to patient reported outcomes guiding care in Pituitary Centers of Excellence, to special workshop/training sessions for both member and nurse delegates.

On this day we will also vote on the wonderful posters supplied by our members.

Sunday, October 4:

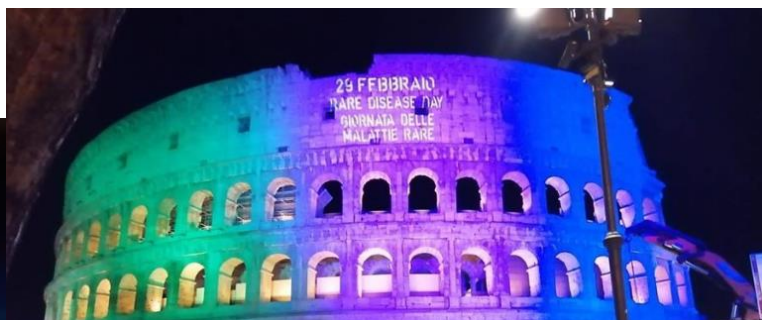
More best practices regarding 'Regional problems and possible solutions'. The remainder of the program has yet to be confirmed.

RARE DISEASES DAY: 29 FEBRUARY

Below we share with you some beautiful international photos in support of Rare Diseases Day. Check out this video as well – [Click Here](#)



Sydney Opera House, Sydney Australia



Above: Colosseum, Rome, Italy

Below: BP Place Stadium, Vancouver BC, Canada



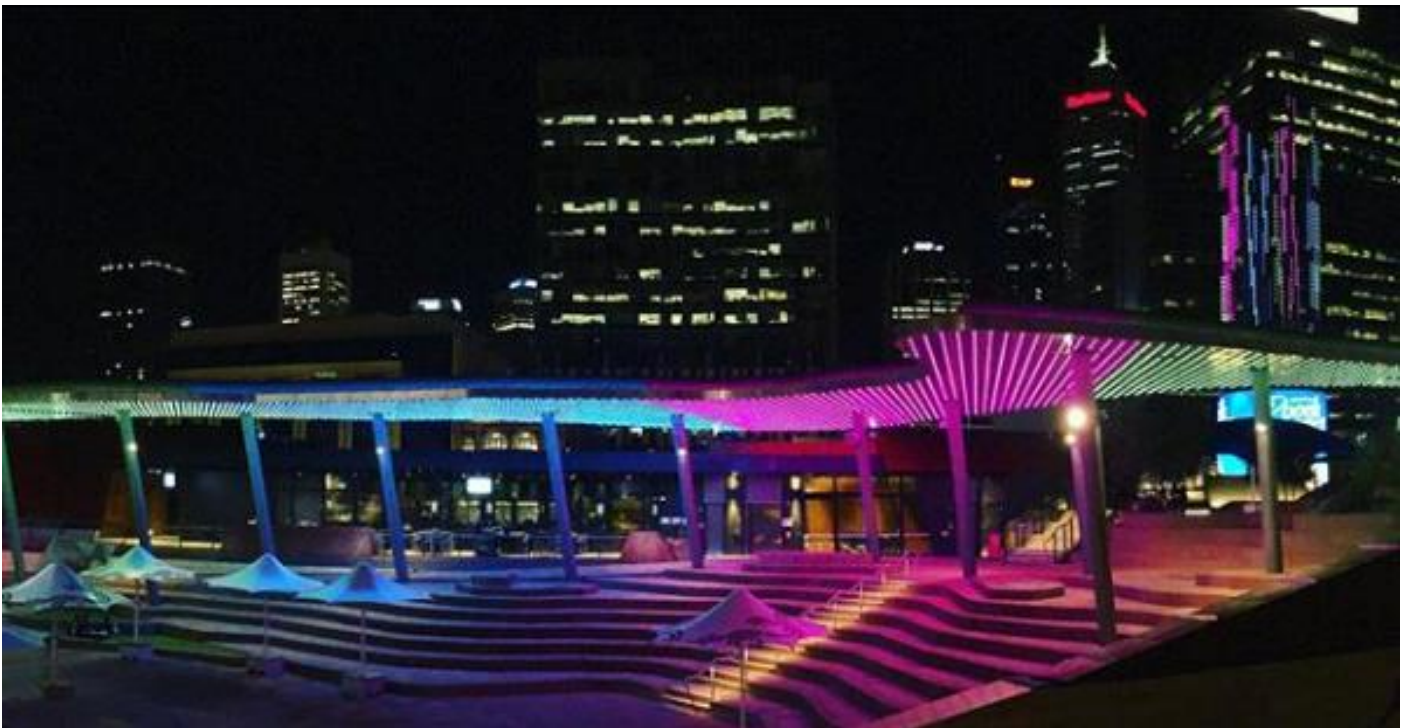


Left: Burj Khalifa, Dubai, Saudi Arabia



Right: Empire State Building, New York, USA

Below: Yagan Square, Perth Australia



CUSHING'S AWARENESS DAY: 8 APRIL

Cushing's Awareness Day is celebrated on April 8th every year. Why 8th April? It is the birthdate of Harvey Cushing. Dr Cushing was the first exclusive neurosurgeon for Cushing's Disease.

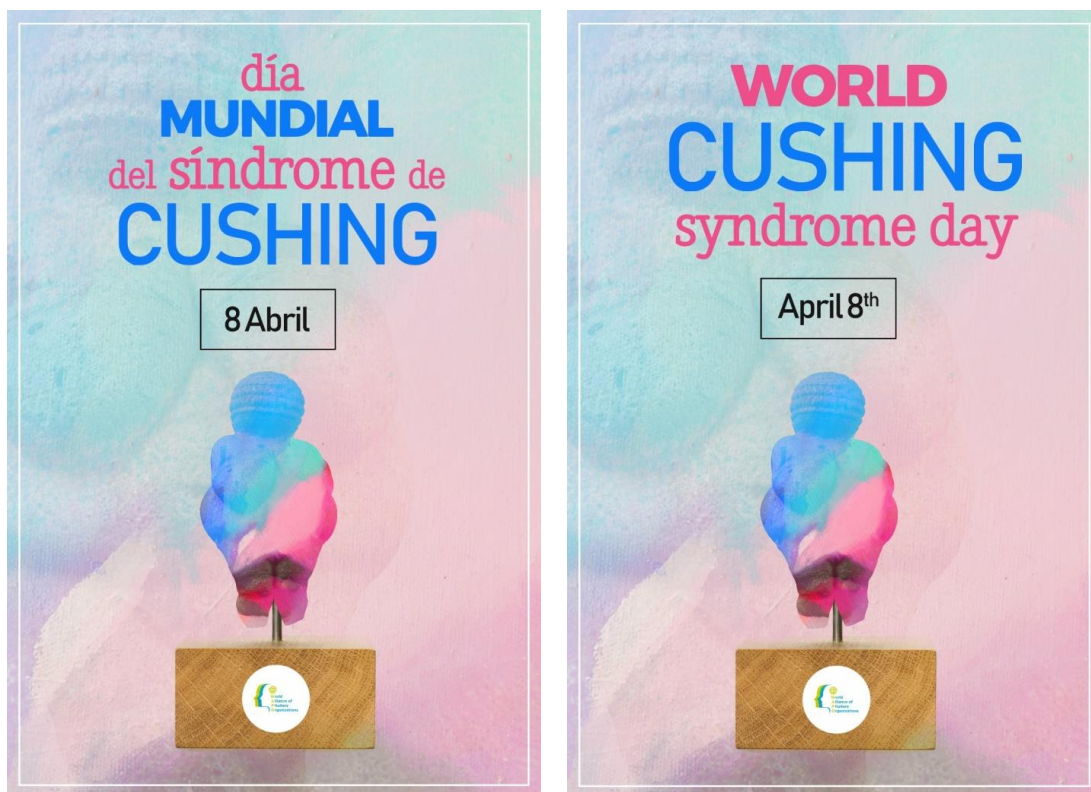
Cushing's name is commonly associated with his most famous discovery, **Cushing's disease**. In 1912 he reported in a study an endocrinological syndrome caused by a malfunction of the **pituitary gland** which he termed "polyglandular syndrome." He published his findings in 1932 as "The Basophil Adenomas of the Pituitary Body and Their Clinical Manifestations: pituitary Basophilism".

In the beginning of the 20th century, Dr. Cushing developed many of the basic surgical techniques for operating on the brain. This established him as one of the foremost leaders and experts in the field. Under his influence neurosurgery became a new and autonomous surgical discipline.

- He considerably improved the survival of patients after difficult brain operations for intracranial tumors.
- He used **X-rays** to diagnose brain tumors.
- He used electrical stimuli for study of the human sensory cortex.
- He played a pivotal role in development of the Bovie **electrocautery** tool with **William T. Bovie**, a physicist.
- He was the world's leading teacher of neurosurgeons in the first decades of the 20th century.

Source: Wikipedia 2020

WAPO MEMBERS ARE ENCOURAGED TO USE OUR SIGNATURE CUSHING'S AWARENESS DAY POSTERS TO PROMOTE THE UPCOMING EVENT. THESE WILL BE DISTRIBUTED TO YOU SHORTLY.



FDA APPROVES NEW TREATMENT FOR ADULTS WITH CUSHING'S DISEASE

The U.S. Food and Drug Administration today approved Isturisa (osilodrostat) oral tablets for adults with Cushing's disease who either cannot undergo pituitary gland surgery or have undergone the surgery but still have the disease. Cushing's disease is a rare disease in which the adrenal glands make too much of the cortisol hormone. Isturisa is the first FDA-approved drug to directly address this cortisol overproduction by blocking the enzyme known as 11-beta-hydroxylase and preventing cortisol synthesis.

“The FDA supports the development of safe and effective treatments for rare diseases, and this new therapy can help people with Cushing's disease, a rare condition where excessive cortisol production puts them at risk for other medical issues,” said Mary Thanh Hai, M.D., acting director of the Office of Drug Evaluation II in the FDA's Center for Drug Evaluation and Research. **“By helping patients achieve normal cortisol levels, this medication is an important treatment option for adults with Cushing's disease.”**

Read the FDA press release: <https://www.fda.gov/news-events/press-announcements/fda-approves-new-treatment-adults-cushings-disease><https://www.fda.gov/news-events/press-announcements/fda-approves-new-treatment-adults-cushings-disease>

March 6, 2020

EURODIS – THE VOICE OF RARE DISEASES PATIENTS IN EUROPE

Parliamentary Advocates for Rare Diseases working towards a new EU policy framework for rare diseases.



At a Policy Event organised at the European Parliament in Brussels last month, EURORDIS re-launched the Network of Parliamentary Advocates for Rare Diseases, a group of European and national members of parliament advocating to improve the lives of the 30 million people living with a rare disease in Europe. Encourage your local MP or MEP to become a Parliamentary Advocate for Rare Diseases!

Patient advocate Fernanda participated in the Policy Event and shared her experience of a recent diagnosis of the rare disease alpha-1 antitrypsin deficiency.

Read here <https://www.eurordis.org/news/parliamentary-advocates-rare-diseases-working-towards-new-eu-policy-framework-rare-diseases>

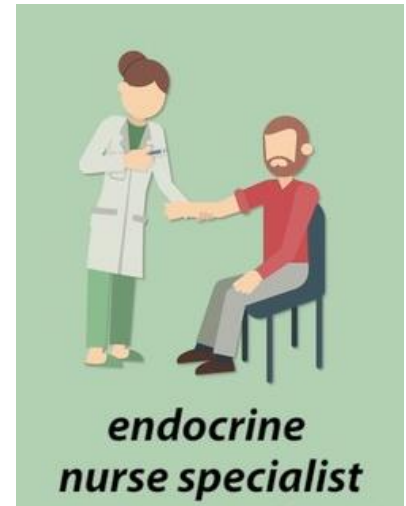


INTERNATIONAL YEAR OF THE NURSE



The definition of a nurse:

- To go above & beyond the call of duty
- The heart and soul of caring
- Who will pass through your life for a minute and impact it for eternity
- An empowered individual whom you may meet periodically, but who will put you and yours above theirs



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 content 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.

APRIL 2020

8 April – International Cushing's Day, GLOBAL

13 to 14 April – [Endocrinology & Metabolic Syndrome](#), Auckland, NEW ZEALAND

15 to 16 April – [14th European Diabetes & Endocrinology Congress](#), London, UK

17 to 18 April – [3rd Global Meeting on Diabetes & Endocrinology](#), Kuala Lumpur, MALAYSIA

20 to 21 April – [International Conference on Diabetes, Endocrinology & Obesity](#), Florence, ITALY

20 to 21 April – [Endocrine Nurse Update 2020](#), Birmingham, UK

MAY 2020

2 to 5 May – [Pediatric Endocrine Society Annual Meeting](#), Philadelphia, PA, USA

6 to 10 May – [American Association of Clinical Endocrinologists \(AACE\) 29th Annual Scientific & Clinical Congress](#), Washington, DC, USA

14 to 16 May – [Living Rare; Living Stronger Forum](#), Cleveland, Ohio, USA

15 to 16 May – [The European Conference on Rare Diseases & Orphan Products \(ECRD\)](#), Stockmsmässan, Stockholm, SWEDEN

23 to 26 May – [The 22nd European Congress of Endocrinology](#), Prague, CZECH REPUBLIC

29 May – [Update on Treatment of Pituitary Tumors](#), NYC, USA

WEBSITE

All WAPO members have received information how they can log in and choose a new password in December 2019.

Recently we have added updated information on the website, incl. a new world map with countries where we have WAPO member organizations.

If your organization has interesting pituitary related information, we'd like to share this on our website as well.

SOCIAL MEDIA

If you are a full WAPO member, and a Pituitary Patient Organization – have you subscribed to 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.

<https://www.facebook.com/groups/211299052873636/>



GOTTA KEEP IT LIGHT!

Funny Nurse Jokes & Puns:

- Nurse to doctor, "There's a man in the waiting room who thinks he is invisible."
Doctor, "Tell him I can't see him."
- What do you call two ITU nurses holding hands?
A synapse.
- Doctor to nurse, "How is the child who swallowed a few quarters doing?"
Nurse, "No change."
- Patient to nurse, "Will I be able to play the guitar after this operation?"
Nurse, "Yes, of course."
Patient "That's great because I couldn't before."
- Why did the doctor tell the nurse to walk quietly past the medicine cabinet?
So they wouldn't wake the sleeping pills.
- How many nurses does it take to screw in a lightbulb?
None, they just get a nursing student to do it.
- Doctor to nurse, "Did you take this patient's temperature?"
Nurse, "No. Why is it missing?"
- Why did the nurse go to art school?
So they could learn to draw blood.
- What's It Called When A Hospital Runs Out Of Maternity Nurses?
A mid-wife crisis!
- Why do nurses bring red magic markers into work?
In case they have to draw blood.
- *You should always be kind to nurses. Remember they choose your catheter size.*





WAPO Summit 2018

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Twitter: WAPO_org

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FACEBOOK

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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

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