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.
CONTENTS

CONTENTS ........................................................................................................................................... 2
VICE CHAIR’S REPORT .......................................................................................................................... 3
WHAT SOME ORGANIZATIONS ARE UP TO ......................................................................................... 4
  NORWAY ........................................................................................................................................... 4
  AUSTRALIA ....................................................................................................................................... 6
  ECUADOR .......................................................................................................................................... 7
  USA .................................................................................................................................................. 12
PITUITARY WORLD NEWS .................................................................................................................... 14
  SPAIN ............................................................................................................................................... 15
  USA .................................................................................................................................................. 18
  UNITED KINGDOM ............................................................................................................................ 20
FEATURE ARTICLE
  SERVICE DOGS FOR CUSHING’S AND AI PATIENTS ................................................................. 21
  PATIENT STORY ............................................................................................................................... 23
WAPO INTERNATIONAL ACTIVITIES .................................................................................................... 25
WAPO SUMMIT 2020 – 5TH CELEBRATION ....................................................................................... 28
ENDOERN REPORT ............................................................................................................................... 28
WAPO CALENDAR OF EVENTS ................................................................................................................ 31
WEBSITE ............................................................................................................................................. 32
WELCOME TO NEW MEMBER ORGANIZATIONS .............................................................................. 32
GOTTA KEEP IT LIGHT ........................................................................................................................... 33
CONTACT US ....................................................................................................................................... 34
Dear WAPO members and friends,

We are already approaching the end of 2019 and it has been a very busy year for all of us! Following the incredibly successful Summit in Lyon, France and our presence at the European Congress of Endocrinology, we launched a very successful global acromegaly campaign, as well as participating in several conferences and workshops in Europe right up to December.

I’m very pleased to see that the members’ news section really stretches to the four corners of the Earth: Norway, Australia, Ecuador, USA, Spain and the UK. All member organizations shared extremely valuable activities, some of which were also life-saving, such as the emergency injection course reported by the Norwegian organization. Perhaps the most pleasantly surprising news concerned the Service dogs for Cushing’s and Adrenal insufficiency (AI) from the Pituitary Foundation UK and the Tai-chi lessons by FAETH, Ecuador!!

As you all know, the 2020 WAPO Summit will be held from 20 to 22 March in Buenos Aires, Argentina and we are in the process of finalizing the agenda, the first event in Latin America. If you haven’t already confirmed your participation, please do so by February 15, 2020!

We hope you will enjoy and share this latest edition of our newsletter and take this opportunity to wish you the very best Season’s Greetings for the festive period ahead!

Best wishes,

Sheila Khawaja

WAPO Vice Chair
WHAT SOME ORGANIZATIONS ARE UP TO

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

NORWAY

Youth conference September 2019, at Svarstadhytta, Norway.

This fall the Norwegian Addison Association arranged its second youth conference, at Svarstad cabin, one hour south of Oslo.

All in all, there were 13 participants from various parts of the country; from Tromsø in the far North to Flekkefjord in the South; and even some coming all the way from Denmark. Participants ranged in age from 22-39; with various diagnoses and combinations of these.

During the stay the participants spent a lot of time talking and getting to know each other, socializing and eating meals together. There was also a hot tub and a sauna (which was used carefully), which was very enjoyable and a great way to relax for tired and aching bodies.

There was a presentation held by Dr. Åse Bjorvatn Sævik, an MD and PhD student at the Department of Clinical Science at University of Bergen, Norway. She told us about the recent study done by herself and colleagues at UiB, looking at residual adrenocortical function in Addison’s disease.

The study is not yet published, and so we cannot disclose many details about it other than the conclusion: Residual cortisol production in Addison’s patients is a reality, and is more common than expected. The publication will be out next year (2020). She also talked about Addison’s in relation to pregnancy and breastfeeding, exercise, libido and other aspects of the disease, which was very helpful and educational for all. The topics were discussed further among participants during the stay and created more opportunities for learning and getting to know one another.
Since the conference was held at a self-serve cabin, all meals were prepared and consumed by the participants and the organizers together, which created more opportunities for chatting and getting to know each other in a more personal and up-close way than would have been possible had the conference been held at a hotel or conference centre. We would highly recommend this type of arrangement for other organizations as well.

Everyone had a great time, and there was a shared feeling between participants that this had been an opportunity for everyone to feel less alone with their chronic illness. More conferences of this kind are needed, also in an international context.

The next national members conference is in Stavanger in June 2020.

We are happy to be a part of WAPO and look forward to seeing some of you at the Summit 2020 in Buenos Aires; both Kari Aas Hystad and Ida Knudtzon have booked tickets.

Ida Margaret Knudtzon, December 2019
September 2019, we held a patient information session at “St. Vincent's Centre for Applied Medical Research” in Sydney, for over 80 attendees.

We heard from one of our Board members about her journey to diagnosis and suffering from Cushing’s disease - a journey which resonated with many in the audience.

We then heard from great medical professionals from “St Vincent’s Private Hospital Sydney” and the “Garvan Institute for Medical Research” about predicting clinical outcomes of pituitary surgery, what to expect pre & post endoscopic surgery, the growth hormone & PBS criteria landscape, how to manage sick days & adrenal crisis, myths & realities of pituitary surgery & new & emerging treatments for pituitary tumours.
In May earlier this year, we held a “Pituitary Twilight” Education Seminar at the Epworth Hospital in Melbourne with over 50 attendees including 15 patients/support people, 5 medical doctors and over 30 nurses. The breadth of discussion was refreshing and all in attendance gained a lot from the 3 hour session. In particular the talk from a member on his patient journey "From Diagnosis to Treatment to Recovery" was raw and emotive revealing that so much more than medical care is needed in this journey.

Malini Raj, December 2019

ECUADOR

Actividades realizadas por la conmemoración del Día Mundial de la Concientización de la ACROMEGALIA

1 de Noviembre
Día Mundial de la
Concientización de la Acromegalia

Caminata y casa abierta en Malecón 2000

27 de Octubre del 2019:

1- 9:00 A.M Caminata en Malecón 2000, visibilizando y concienciando la ACROMEGALIA.
2- 10:00 A.M Casa abierta malecón 2000
3- Charla educativa sobre la enfermedad
4- Testimonio de pacientes.
5- Alertando de los síntomas de la Acromegalia
6- Demostración de prácticas de Tai Chi con el maestro Jing Ming Guo Presentación de Abanico y Espada
7- Introducción al Tai Chi con la participación de los pacientes, médicos y público
8- 12:00 A.M Clausura, refrigerio y entrega de material educativo para el paciente
En la ciudad de Guayaquil, se dio con mucho éxito la caminata haciendo conciencia y visibilizando sobre la **ACROMEGALIA**, Pacientes familiares, amigos y médicos especialistas que tratan a pacientes con Acromegalia, caminan con pancartas alusivas, empezando a la altura de la calle Padre Solano y culminando a la altura de Junín, sector 7 explanada Orellana

En la explanada Orellana fue instalada una casa abierta para proporcionar información a los asistentes sobre la enfermedad, Margarita Vásquez presidenta de Fundación de Apoyo a Enfermos con Trastornos Hipofisarios FAETH, da la bienvenida a los asistentes explica, que esta actividad se está dando por conmemorarse el día mundial de la Concientización de la Acromegalia, el próximo 1 de Noviembre y la importancia de realizar estas acciones ya que la Acromegalia es una enfermedad Rara y de difícil diagnóstico, agradeciendo a los presentes su asistencia. Algunos miembros de FAETH, se encargan de invitar a los visitantes del Malecón 2000 a acercarse al stand, se entrega material informativo.

El Dr. Roberto Cedeño, médico que trata a pacientes con Acromegalia dio una charla educativa a los asistentes sobre la enfermedad, sus complicaciones si no es tratada oportunamente y resaltando que estas actividades de concientización y difusión de la enfermedad son muy beneficiosas para ayudar a obtener un diagnóstico oportuno, dice sentirse satisfecho que los pacientes sean los que se muestren al público y compartan sus experiencias y testimonios, felicitando a los organizadores por esta actividad.

Luego se invita a todos los asistentes a uniese al ejercicio en la práctica del Tai Chi, ejercicio muy saludable para el cuerpo, alma y espíritu, sus suaves movimientos son recomendables para personas que sufren de dolores articulares, ayuda a la concentración y al equilibrio.

![Caminata en Malecón 2000 | Walk in Malecon 2000](image)
CASA ABIERTA COMPARTE INFORMACIÓN, ALERTANDO DE LOS CÍNTOMAS DE LA ACROMEGALIA
| STALL – SHARING INFORMATION & ALERTING PEOPLE ABOUT THE SIGNS OF AGROMEGALY
Día Mundial de la Concientización de la Acromegalia

Hospital de Especialidades Guayaquil Dr. Abel Gilbert Pontón.

31 de octubre 2019

1- 9:00 A.M Caminata
2- 10: A.M Sesión solemne auditorio Torre Consulta Externa
3- Creación Club Acromegalia HAGP
4- Firma acta compromiso entre pacientes y el Hospital
5- Entrega de credenciales
6- Entrega de placas de agradecimiento a las autoridades del Hospital.
7- Entrega de material educativo para el paciente, refrigerio y cierre con número musical.

CAMINATA: En el Hospital de Especialidades Guayaquil Dr. Abel Gilbert Pontón, se reúnen los pacientes Acromegálicos y son acompañados por las autoridades del Hospital, Dr. Francisco Ceballos (Gerente Hospitalario), Dr. Luiggi Matini (Director Asistencial), Dra. Yadira Arnao (Subdirectora de especialidades Clínicas), Dr. Roberto Cedeño (Líder del área de Endocrinología), Ingeniera Hiralda Alvarado (Líder de Atención al Usuario) entre otros médicos de esta casa de salud, para juntos caminar por las calles alrededor del Hospital, con el afán de hacer visible la Acromegalia y de esta manera unirse a la conmemoración del Día Mundial de la Concientización de la Acromegalia.
November 1, 2019:

World Acromegaly Awareness Day

Activities for the commemoration of the World Acromegaly Awareness Day

Walk and open house in Malecon 2000

October 27, 2019:

1- 9:00 A.M Walk on Malecon 2000, to raise awareness and visibility of ACROMEGALIA
2- 10:00 A.M Open house Malecon 2000
3- Educational talk about the disease
4- Patient testimonies.
5- Warning of the symptoms of Acromegaly
6- Demonstration of Tai Chi practices with maestro Jing Ming Guo - Presentation of Fan and Sword
7- Introduction to Tai Chi with the participation of patients, doctors and the public
8- 12:00 A.M Conclusion, snack and delivery of patient educational material

In the city of Guayaquil, the walk successfully raised awareness and increased visibility of ACROMEGALY. Family, patients, friends and medical specialists who treat patients with Acromegaly, walk with banners, starting at the height of Padre Solano Street and culminating at the height of Junín, sector 7 Orellana Esplanade.

An open house at the Orellana Esplanade, provided information to the attendees about the disease. Margarita Vásquez, president of the Foundation for Support for Patients with Pituitary Disorders FAETH, welcomes the attendees, explains that this activity is being commemorated on World Acromegaly Awareness Day next November 1, and talks about the importance of performing these activities further explaining that Acromegaly is a rare disease, difficult to diagnose, and thanks those present for their assistance. During the proceedings, members of FAETH, distribute informational materials.
Dr. Roberto Cedeño, who treats patients with Acromegalia talked about the disease’s complications if it is not treated in a timely manner, and highlighted the importance of awareness and dissemination of information to achieve early diagnosis. Dr. Cedeño mentioned he is pleased that patients are participating in public awareness initiatives sharing their experiences and testimonials and congratulated the organizers for this activity.

All attendees were invited to join in a Tai Chi session, which is helpful for people suffering from joint pain and beneficial in activities that require concentration and balance.

Margarita Vásquez Amoroso, December 2019

The Cushing’s Support & Research Foundation (CSRF) held their biennial patient conference the weekend of 4-6 October, 2019, in Atlanta, Georgia. This meeting was somewhat unique, as the agenda was determined earlier in the year by an all-patient steering committee, and attendees to the meeting had to meet the qualifications of

1) having a confirmed diagnosis and
2) having begun or completed at least one treatment or therapy.

There seems to be an under-met need for more information about how to navigate the “new normal” after treatment. This is especially important for us because it’s rare to have a “one and done” surgery – complications persist for long afterwards, and recurrence is common. Based on these understandings, the agenda was built around the challenges we continue to face in the short and long term after treatment.

The lineup of presenters was stellar - some of the best names in the Cushing’s space and many doctors actively involved in research and clinical trials. As the conference was held on the Emory University Hospital campus at the Emory Conference Center Hotel, we were honored to have the local team of Neurosurgeon Nelson Oyesiku, Neuroendocrinologist Adriana Loachimescu, and Neuropsychologist Suzanne Penna presenting on their expertise. Emory is one of the first major centers to recognize the importance of addressing the neuropsychological changes experienced by Cushing’s patients, and for the last several years patients have been referred to Dr. Penna’s practice for this support. It’s no surprise that her presentation was eagerly anticipated and one of the most praised of the weekend.
The last night of the conference, attendees were invited to a social event in the on-site bowling alley. We ate, we drank, we made a lot of noise! One of the best parts of conferences like this is the opportunity for so many, for the first time, to be surrounded by people who know what it is like to experience this bizarre disease. CSRF was very happy to have JD Faccinetti from Pituitary World News and WAPO’s own Muriel Marks in attendance as well.

The main sessions of the conference were video recorded, and those videos along with handouts and slides from all available sessions are now on the CSRF website at https://csrf.net/patientconference2019 or scan the QR code. CSRF also recorded a special set of four patient story recordings that will be made available as soon as they’ve been edited.
This is a summary of the latest articles and opinions published by Pituitary World News. If you would like additional resources or background from any of the materials published, please contact us.

Podcasts and articles:
Several interesting reviews and podcasts. A few noteworthy follow:

- **A salient podcast on HCG (Human Chorionic Gonadotrophin) focuses on its use with men with hypopituitarism and infertility.** Dr. Blevins focuses his discussion on many of the relevant subjects related to hypogonadism (where the body does not produce enough testosterone), especially as it relates to hypopituitarism, a condition in which the pituitary gland does not produce one or more of its hormones or not enough of them to function normally.

- Sometimes it is through these genuine, unscripted chats that we get insight into what it is like to deal with chronic pituitary disease, in this case, acromegaly. This podcast is no exception. In it, Dr. Blevins and his patient Monica talk about it and deliver a fascinating perspective.

- A fascinating debate in the pituitary world regarding what to call tumors. A side of me wants to yell “Who cares what you call them!!!” Regardless, this could affect us all so it’s important to review it and be aware. Read about it here and contact us if you’d like to participate in the debate. We have access to the materials!

- Nice work by Crinetics with a group of Acromegaly patients. To mark acromegaly day, Crinetics, which is developing an oral drug for the disease and has several other drugs for pituitary disease under development, read more about these drugs here, devised an activity to show its team members what might be like to have to deal with everyday acromegaly challenges such as fatigue, joint pain, headaches, and other insidious conditions. Read more here

- **ON-DEMAND presentation of the PWN - UCSF Pituitary Patient Conference:** PWN sponsored a pituitary patient conference in conjunction with University of California San Francisco (UCSF) You can view the presentations and highlights of the conference “on-Demand” here.

- The National and International Canadian conference this past September in Toronto, Canada, was not only a good time, but also a positive, engaging, interactive, and educational event. The presentations were informational and by all accounts very helpful to a large group of acromegaly patients and their families who gather every two years to catch up, exchange ideas, and learn a few things. Our kudos to the organizers, The Vancouver Acromegaly Support Group leaders Deanna Badiuk, Pieter Dorsman; Peggy McDonald from the Atlantic Acromegaly Support Group. Stay tuned for videos from the presentations.
Read more here about the latest podcasts. This link will take you to all the published podcasts.

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

**WAPO member activities:**

Please visit the WAPO - Pituitary World News joint section “NEWS FROM AROUND THE WORLD”

**Mental and Emotional health**

Our coverage of mental and emotional issues related to pituitary disease continue to get the most attention from readers. Here you can find a comprehensive list of the published materials on Pituitary World News.

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, December 2019

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**SPAIN**

En el mes de Octubre tuvimos la excelente oportunidad de participar de manera activa en el 60 Congreso SEEN, en el norte de España, en Bilbao. Es un congreso anual organizado por la Sociedad Española de Endocrinología y Nutrición donde se dan cita más de mil endocrinólogos de España y otros países para poner en común inquietudes y novedades terapéuticas relacionadas con enfermedades endocrinas. Como algo novedoso en España y muy ilusionante para nosotros los pacientes -por primera vez en estos 60 años- abrieron sus puertas a las asociaciones de pacientes. Distintas asociaciones estuvimos durante los tres días del congreso ofreciendo información desde nuestros stands a todos los asistentes. Entregamos diversos materiales para dar a conocer nuestra labor. Varios socios participaron de manera voluntaria turnándose en el stand, dialogando con todos los endocrinólogos que pasaban por el stand y haciendo así que muchos de ellos nos pudieran conocer y ahora también, puedan hablarles de nosotros a sus pacientes con acromegalia.
Además, tuvimos el honor de participar en una sesión conjunta con el Dr. Moisés Mercado, endocrinólogo mejicano con amplia experiencia con pacientes con acromegalia. En la charla hablamos sobre la humanización de la consulta, la importancia del diálogo médico-paciente y de ir más allá de las meras pruebas médicas como soporte y mejora de la calidad de vida del paciente.

Tanto los días del congreso, como el poder compartir con endocrinólogos y pacientes la sesión, fueron muy gratificantes. Generamos sinergias muy positivas con distintos profesionales sanitarios muy involucrados en la acromegalia y se abrió una nueva puerta para seguir caminando juntos en pro de los pacientes. Gracias a esta sinergia, la acromegalia ahora tiene más voz entre los endocrinólogos en España, y estamos trabajando en proyectos conjuntos que esperamos den sus frutos en los próximos meses y años.

Al día siguiente del congreso, el 19 de Octubre, celebramos el VII Encuentro Nacional de Pacientes con Acromegalia, organizado por nosotros, la Asociación Española de Afectados por Acromegalia. Este encuentro anual está dirigido a pacientes y a profesionales sanitarios implicados e interesados en la acromegalia para, de esta manera, generar un foro de diálogo entre ambos grupos, fomentar el conocimiento.

Bajo el título “Más allá de la IGF-1”, nos reunimos más de un centenar de pacientes, familiares y profesionales sanitarios para poner en común inquietudes y novedades sobre la acromegalia y la calidad de vida de las y los afectados por esta patología endocrina. Este año batimos record de asistentes y queremos que cada año seamos más y más.

¡Fueron unos días tan intensos como reconfortantes!!
In October we had the excellent opportunity to participate actively in the 60th SEEN Congress in Bilbao, in the north of Spain. It’s an annual meeting - organized by the Spanish Society of Endocrinology and Nutrition - where more than one thousand endocrinologists from Spain and other countries meet to share concerns and therapeutic developments about endocrine diseases.

As something new in Spain and very exciting for us (patients), for the first time in 60 years, this congress opened its doors to patient organizations. Some organizations could be - during the three days - in a stand offering information to all the endocrinologists that attended the meeting. We gave them different materials to publicize our work as an organization. Several members participated voluntarily in the stand, talking to all the doctors and making them know us, so now they can also inform about us to their acromegalic patients.

Also, we had the honor of being part of a joint session with Dr. Moisés Mercado, a Mexican endocrinologist who is an expert in acromegaly. In this meeting we talked about the humanization of medical care, the importance of doctor-patient communication, and going beyond medical tests to support and improve the patient’s quality of life.

These days in the congress, sharing our reality with endocrinologists and patients, were very gratifying. We created very positive synergies with a lot of health professionals involved in acromegaly and we opened a new door to continue walking together for the patients. Thanks to this union, acromegaly is now more known by endocrinologists in Spain, and we are working together in some projects which we hope will succeed in the following months and years.

The day after SEEN Congress, October 19th, we organized the VII National Meeting of Patients with Acromegaly. This annual meeting, organized by us (Spanish Organization of Patients with Acromegaly) is aimed at patients and health professionals interested in acromegaly to create a dialogue between both sides and promote knowledge about acromegaly.

Under the title "Beyond IGF-1" we gathered more than one hundred patients, family members and health professionals to share concerns and news about acromegaly and the quality of life of acromegalic patients. This year we broke the record of attendees and we wish to continue growing year by year.

What intense, wonderful and comforting days we had!

Raquel Ciriza, December 2019
The Pituitary Network Association has been busy these last few months with our pituitary awareness and education campaigns.

On Saturday, September 14th the Pituitary Network Association joined forces with The Ohio State University Pituitary Center for the Ohio Pituitary Patient Symposium 2019 hosted at the The James Comprehensive Cancer Center in Columbus, OH. Held in conjunction with the OSU Pituitary CME Symposium, the day was filled with a series of 11 pituitary and hormonal education sessions presented by experts in pituitary medicine with the most up-to-date information on pituitary disorders and treatment. Keynote speaker Maria Fleseriu, MD, FACE from OHSU in Portland, OR spoke on Hypopituitarism and Daniel Prevedello, MD the OSU Pituitary Program Co-Director gave a riveting talk on the Surgical Approach: What to Expect with video of an actual surgery.

Dr. Luma Ghalib, MD, endocrinologist and esteemed member of the OSU pituitary team spoke on the Psychosocial Implications of Pituitary Disease, a subject that is of interest to many patients. The Radiation Therapy session was especially interesting, detailing how the future of this therapy will be able to be more precisely administered. All of the presentations had the audience captivated; here are not enough words to convey how amazing each and every presentation was
During the morning session, patient organizations were given time to present information about their organizations. We were given time to talk about the different ways in which the Pituitary Network Association supports people with pituitary disorders. We were also given the unique opportunity to tell the attendees about the challenges faced by patients that we felt need more attention.

We brought up the psychosocial aspects of pituitary disorders and the challenges faced by not only the patient but their families as well. We also discussed how patients often report that they are told that their hormones are within normal ranges but they do not feel like their symptoms are being controlled to their satisfaction. Both of these topics were acknowledged and discussed by the physician panel and will hopefully lead to future dialog on these topics and improved patient care.

In honor of Pituitary Awareness Month, the PNA took to the streets of Thousand Oaks, CA to raise awareness for pituitary disorders by participating in the Thousand Oaks Rotary Street Fair. With an estimated 19,000 people in attendance, the PNA drew in the crowds by holding a fundraiser, raffling off prizes that were donated by local businesses in the community.

We developed a new handout and gave it out, along with other goodies to people as they walked by. People stopped by to ask, "What is a pituitary?" In addition, several pituitary patients shared their stories and thanked us for being there to spread awareness. It was a hot, blustery day and our four-legged friends were able to enjoy a cool drink of water while their owners stopped in to chat. The people who hung around for the drawing waited with anticipation as the tickets were pulled and the winners announced. Winners were overjoyed as they took their prizes home. It was a truly memorable day!

We are now planning some exciting programs for 2020. Stay tuned!

Carol Knudsen, December 2019
Following on from my newsletter information last month, we are very happy to announce that on 6th November this year our Head of Patient and Family Services, Pat McBride attended the Helpline Partnership Annual Conference in Birmingham with our CEO Menai Owen-Jones, as she had been shortlisted as a finalist in the Helpline Awards. Organised by The Helplines Partnership, these awards recognise and celebrate the amazing work that helplines, their staff and volunteers do providing information, support and advice to improve people’s lives. In addition, they are an opportunity to acknowledge and reflect on excellence at an individual and organisational level.

Pat was shortlisted in the Helpline Employee of the Year category, along with seven others, and it was announced that afternoon that she had been awarded the honour this year. It is a prestigious award, and one that is very well deserved, as Pat has dedicated over 20 years to supporting patients via Helpline services, and continues to do so. She also assists with recruiting and training our telephone Helpline volunteers, and is always on hand to provide information and support to them as well as the people who contact our organisation. In her usual manner, Pat accepted the Award for the whole team, and asked for no photographs to be taken - so sadly I cannot share any with you. However, I am sure everyone will want to congratulate Pat on this truly amazing success, and for continuing to be a shining example of Helpline services at their best.

Further recognition came with our CEO being invited to National Council for Voluntary Organisations Special Lecture on Tuesday evening 26 November. During the drinks reception, HRH The Princess Royal will be meeting small groups of guests, and Menai has been selected for inclusion in one of the meet and greet groups. As I write this, Menai is en-route to the venue, and will be reporting back in the next few days. She has indicated she is hoping for an opportunity to inform HRH of pituitary disease, and the impact they have for individuals living with it.

We have a new member of staff - James Charlick began working for us on 15th October as our Assistant Administrator (part time) covering Mon- Fri mornings. He is assisting Miranda Payne at our National Support Office in Bristol, covering all aspects of the business.

We are sorry not to be able to attend the WAPO Conference in 2020, but WAPO continues to be an important partnership, and we hope the event is as successful as previous years have been.

All that is left to say is that everyone at the Pituitary Foundation wish you all a happy and healthy festive season, and a peaceful and successful 2020.
SERVICE DOGS FOR CUSHING’S AND AI PATIENTS

CSRF member and Cushing’s survivor Amy Dahm, accompanied by her service dog, Sam, co-facilitated an informal discussion with renowned dog trainer Bill Creasy about service dogs for Cushing’s and patients with adrenal insufficiency (AI) as a side meeting to the National Cushing’s Patient Education.

Bill Creasy has over 40 years’ experience training dogs and is a renowned scent dog trainer. The goals of the presentation were to inform the audience, examine the current landscape for Cushing’s and AI service dogs, and to eventually create a replicable, reliable protocol for training adrenal insufficiency dogs.

Ms. Dahm defined an adrenal insufficiency dog and presented an overview of the Americans with Disabilities Act (ADA) and legal protections for service dogs and their owners. She defined an Adrenal Insufficiency Dog (AID) as a dog trained to perform specific tasks which can detect changes in cortisol in the body and alert a patient when the patient is heading into medical crisis. Under the ADA, a service animal is defined as a dog that has been individually trained to do work or perform tasks for an individual with a disability. Service providers are only allowed to ask two questions:
1) Does the owner have a disability?
2) Does the dog assist the owner with that disability? The tasks performed must relate to the disability.

She compared service vs. therapy vs. emotional support dogs, and noted that the category of service animals is the only category that has legal protection under the ADA, although some airlines and housing boards do recognize emotional support animals (ESAs). State law also comes into play. For example, for service dogs in training, trainers must follow state law, not the ADA.

Although the interest is keen throughout the Cushing’s and AI communities, at this point, efforts have been one-off and it is difficult to obtain a reliably trained AID.

Traditionally, there are three ways to obtain a service dog:
1) from a professional trainer and/or specialty organization
2) to train one yourself
3) to have the dog alert naturally.

Although there is an online group dedicated to training service dogs for “Cushies” (Cushing’s patients), at this point in time, there is no recognized, replicable training protocol for adrenal insufficiency dogs in the United States. There are at least a few vetted AI service dogs in Europe. According to experienced Diabetic Alert Dog (DAD) trainer Becky Causey, the standard she recommends for training is that the trainer has trained a service dog focusing on that specific disability that has successfully alerted over the course of one year. Mounting interest from the Cushing’s and AI communities, coupled by a burgeoning awareness by experienced dog trainers, is leading to a new push for developing a reliable source of trained medical alert dogs.
Benefits

The potential benefits of developing a reliable, large pool of AIDs are many. Medical alert dogs serve as an additional disease management tool for those patients dealing with the day-to-day management of a very tricky disease where there are very few tools available.

Until extremely recently, there was no way for patients to check their cortisol levels on an immediate basis – and the accuracy and authenticity of the iPhone meter is still unknown long-term and it is expensive and not commonly available.

A reliable medical alert dog can provide an alert to a patient when heading into crisis, buying the patient more time to take more steroids, self-inject, or head to the ER for treatment. If a patient loses consciousness during crisis, a service dog can alert bystanders. A trained dog can fetch extra steroids if the owner becomes incapacitated, and has the extra benefit of making an “invisible” disability more visible, accepted, and accessible.

Renowned trainer Bill Creasy has been studying the mechanics of Cushing’s and adrenal insufficiency and is planning on applying his refined training and scent-work methods to an attempt to train a new AI dog. He estimates that, if successful, it will take 18 months to train the puppy to be a fully functional, public access AI service dog. He hopes to use this dog as a template for proof-of-concept and for developing a replicable protocol for training other AI dogs.

In order to secure a new dog, a client would pay $2000 upfront and then make monthly payments for a total of $18,000 (roughly $1000/ month for each month of training).

Challenges

There are several challenges facing efforts to develop a replicable, reliable protocol. Cortisol is not easily measured, and every “Addie” (patient with Addison’s) has a different cortisol “cliff” at which point they begin to nose dive into an adrenal crisis. This is cutting edge science. It’s not clear that all Addies emit a “scent” when going into crisis.

The Service Dog Industry

Per renowned trainer Becky Causey, a potential service dog owner should practice “buyer-beware.” The service dog industry is not regulated, is highly fragmented, and there is no one standard. A trained service dog, for example a diabetic alert dog, can cost anywhere from $15,000 on the low end to $25,000-$30,000 (US) on the high end, depending on the skill level and seniority of the trainer. Many illnesses have organizations dedicated to funding and helping train service dogs geared towards the needs of patients with those particular illnesses; Cushies and Addies do not.
**Vetting a Service Dog Trainer**

Per Becky Causey, these are the questions you want to pose before spending thousands of dollars and hundreds of training hours on a service dog charged with assisting in life-threatening situations:

- How many Addison’s or Cushing’s dogs have you successfully trained? And how long have they successfully been working with their owners?
- What is the motivation for training a dog with this skill? Personal first-hand knowledge of disease, personal interest, or paycheck?
- Does the trainer understand the mechanics of the disease?
- Is the trainer training towards the dog providing helpful tasks or preventing a life-threatening emergency?

Originally submitted and published in the Cushing’s Support and Research Foundation newsletter. Re-published with author’s permission

**PATIENT STORY: Amy and Sam’s Story**

After developing post-operative adrenal insufficiency after my ULA in 2014, my beloved dog, Sam, spontaneously alerted one me one night when I was home alone on the couch with a raging cortisol headache. Sam is a Cyprus poodle, and he was a hunter with a strong sense of smell. I didn’t feel well, and he alerted - he issued a piercing shriek, he jumped on the couch, and he started pawing at my hair and nudging me. I took steroids, and he calmed down. Puzzled, I lay back down and rested.

The next day, after googling and finding a story for an Addison’s dog in the UK and realizing that he might have been alerting me, I wanted to learn more about service dogs and make Sam legit. I lived in mortal fear of having an adrenal crisis, lived by myself, and had problems with my balance and frequently dropped things.

Despite my best efforts, including researching online, consulting my vet, and asking the online groups, I hit a brick wall. I couldn’t tell what my local service dog laws were, where I could get Sam properly trained, or what the standards were. One night I was home watching TV and a news segment came on about a renowned service dog trainer. I called her the next day and attended a service dog workshop geared towards service dog owners an hour outside DC.

At this workshop, she tested Sam and other dogs, educated us on the basic tenets of the ADA, and introduced me to other trainers, including Becky Causey. The final day of the workshop the dogs rode public transportation and did a check-out in a nearby town, and Sam passed with flying colors. Both Sam and I were exhausted, and would take two-hour naps when we got back to the hotel. By the end, he would not even look at me – his journey from a pampered pet to a full-on service dog was not an easy one for him.
Over the next few months, my boyfriend and I would take Sam and practice what we had been trained to do. We slowly exposed him to an increasing amount of stimuli in varying controlled environments, and gave him attention when he behaved well (and cut off attention when he didn’t). He hated the service vest, and chafed at wearing it. Sam, who was very social, was upset that his meet and greets were sharply curtailed. We visited restaurants, attended lectures, and took him to other people’s houses in an effort to expose him to additional stimuli. I sought out empty daytime movie theatres to see how he would react to the big screen.

The question remained whether his initial alert was a fluke or if he could repeat it. Eventually, we received the answer when he alerted on me again. Although I didn’t feel in crisis, per se, I headed to the ER, where the doctors discovered I had a serious infection that was impacting my cortisol.

My boyfriend and I took Sam to our first meeting of the DC Chapter of the CSRF Support Group in 2015 and he became the unofficial mascot. Although many people recognized he was a social and polite dog, many people were suspicious because he was not the standard issue Labrador service dog. I became tired of explaining over and over again how he was a service dog and educating various business owners about what they could legally ask us. To be sure I was operating within the law, I checked in with the service dog coordinator for DC, who assured us we were. Over time, Sam and I fused as a unit. We became more comfortable walking in stride together, obeying commands, and working as a team.

Sam and I went together to Capitol Hill for Rare Disease Week. While preparing to medically retire, Sam accompanied me to my seminars at the Foreign Service Institute, where U.S. diplomats go for training.

Sam continues to support me, and we hope to use our relationship as a framework for developing a protocol for medical dogs for Cushing’s and AI patients.

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_We encourage you to ask a clinician in your country to write an article of interest for the newsletter, please send to the Editor._
WAPO INTERNATIONAL ACTIVITIES

December 2019

WAPO co-hosted a PEGASUS networking event in Leiden, The Netherlands on December 10th where we had the opportunity to briefly share the history, accomplishments, challenges and future projects of a global organization. The event was organized by admedicum, a German-based company devoted to bringing patient engagement to the forefront in collaborations with industry and other major stakeholders. The collaboration by the team members, among which Philipp von Gallwitz (admedicum Cologne) and Robert Pleticha (admedicum Spain) is transversal, meaning it is not focused on a single disease.

The most valuable take-away from this event is the stark realization that even if there are thousands of rare disease and ultra-rare diseases, there are many aspects of national and umbrella organizations that overlap. It was also refreshing to be able to meet other patient experts from other countries (although mostly from the Netherlands).

Upon return from the event, WAPO received a generous donation from admedicum, as a sign of goodwill in the Christmas Season and in recognition of the dedication and hard work shown by the global organization in patient engagement.

November 2019

WAPO has been collaborating with Patient Focused Medicine Development (PFMD) and the Synergist since earlier this year to develop a how-to-module on lay-language summaries (WG5) of scientific research articles that are published in peer-reviewed journals (mostly online). This last meeting of the year with WG5 was meant not only to consolidate the findings and comments of the Patient Engagement Open Forum that took place in the summer, but also to determine the most appropriate format and channel to share such information. Lay language summaries are required for all clinical trial outcomes from 2020 as per directive according to (EU CTR) No 536/2014.
Such summaries are deemed crucial to increase health literacy of the general population; to increase public perception and willingness to participate in and engage with clinical trials; and to spur the development of new research based on gaps identified by the patient community at large.

The first draft of the how-to-modules should be published by the end of the Q1 in 2020. For more information please refer to the PFMD page.

September 2019

WAPO co-chaired a roundtable in the 2019 Drug Safety event that was held in Amsterdam on 10-11 September. Sheila Khawaja and Muriel Marks both attended the event and shared their thoughts on the current situation and discussed with other participants at the table (about 15-20). The invitation to co-chair was a direct result of WAPO’s attendance as a delegate in 2018 and the observation that the number of patient representatives and the issue of engaging with patients was a topic that was not very much present on the agenda. In the 2019 edition, patient engagement and participation had increased.

LEFT: WAPO vice-chair, Sheila Khawaja, co-chairing the session together with Matthias Boedding (Head of Global Drug Safety Medicine, Merck) and Rachna Bedi (Renal Pharmacist, Imperial College Healthcare NHS Trust)
RIGHT: A second group also met on September 11 and all agreed to join our voices and work together.
BELOW: Sheila and Muriel with some of the participants from the roundtable on September 10th.
Following the WAPO Summit in Lyon, and after an email exchange, Sheila had the honor of visiting the Pituitary Foundation UK and meeting Menai Owen-Jones, CEO of the Foundation; Martin Cookson, responsible for finance and resources as well as keeping the membership database up to date; Sian Pitman, working on events and volunteer management; and last but not least, Jay Sheppard, head of fundraising. It was really an amazing to meet so many staff members as it was summertime, and many were off on holiday.

The purpose of this short visit was to learn and observe how a 25-year old foundation is organized and evaluate if any take-aways from the visit could be adapted to a global organization. Sheila also had the opportunity to speak to two helpline nurses (Pat McBride was one of them) who provided some insight on what it means to be such a vital line of support to patients from across the UK. None of this would have been possible without Sammy Harbut (occupational therapist and patient and family services coordination within the Pituitary Foundation, an unforgettable host and a crucial spokesperson in defining the details to enable Sheila to visit the Foundation). WAPO is extremely grateful for this exchange and looks forward to establishing new collaborative opportunities in 2020.

Sheila Khawaja. December 2019
5TH SUMMIT CELEBRATION

2020 will be an exciting year for WAPO! It is hard to believe that we will be 5 years strong!
Over this time many leading advocates from pituitary organizations have been able to meet at our Summits.
The sharing of best practices and resources has been of great benefit, especially for the smaller
organizations. As we grow we are also mentoring new start up organizations in various countries and
welcome them as Associate Members.

To celebrate we will be holding the Summit in Buenos Aires, Argentina, March 20 to 22, 2020.
The program is almost done, and it certainly will be one with a difference. It is hoped that invited nurses in
Latin America will join us for the Saturday program, so that we can support them in their Endocrine/pituitary
education.

The World Health Organization (WHO) declared 2020 ..
Year of the Nurse!

An email of invitation has been sent to our members, offering an early bird registration and an incentive
to book the flights early to help us preserve our costs. It would be appreciated if you could reply to the
email indicating your intention to attend, as our accommodation booking has to be finalized early in the
New Year.

Sue Kozij, December 2019

ENDO ERN REPORT

ENDO-ERN 'cherishes' rare endocrine disorders What is rare, a unique painting, a unique building,
deserves extra attention. This is also the case with rare diseases. The development and
dissemination of knowledge about these diseases require extra attention. For this reason, for several
years now the EU has had ERNs, European Reference Networks. These are virtual networks in which
doctors and patients in Europe share their knowledge of and experiences with rare diseases. ENDO-
ERN 'cherishes' the rare endocrine disorders. Take a look at https://endo-ern.eu/
It sounds paradoxical: rare diseases are not rare at all. After all, in the Netherlands there are an estimated one million people diagnosed with a rare disease. Moreover, in the European Union there are in total around 30 million people diagnosed with a rare disease. The rarity of the rare diseases only becomes clear when you consider that this is a collection of many thousands of different disorders. For each disorder, we are talking about a few dozen to, at most, a few thousand patients (in the Netherlands). Officially, a condition is qualified as 'rare' if the disease occurs in less than 1 in 2000 people. Translated into Dutch terms, this means that a disease is rare if fewer than 8,500 patients in the Netherlands are diagnosed with the disease.

The fact that a disease occurs in only a few people is in itself pleasant. The fewer people suffer from a disease, the better. However, for people who do suffer from a rare disease, its rarity is a (major) disadvantage. For them, the medical circuit is sometimes a real obstacle course. To start with, it often takes (much) longer before the disease is recognized and the correct diagnosis is made. For example, an GP in the Netherlands has in average only once in every 20 years a patient with a pituitary gland disease in his practice. Particularly if the rare disease has symptoms that also fit a much more common disorder, a doctor will initially focus on this more common disorder. Once the correct diagnosis has been made - which can sometimes take years - the second hurdle follows: the patient often has to undertake an often difficult search to find a medical specialist who has specialized in the rare disease and therefore is aware of all aspects of the disorder. For example, not every internist always has all the knowledge about the treatment of Cushing's syndrome or thyroid cancer. Moreover, it is not uncommon that the scientific knowledge about the development and optimal treatment of rare diseases is limited. After all, unknown, unloved; applies also to (investing in) scientific research. Finally, the patient with a rare disease, more than people with a common disorder such as asthma or diabetes, encounters more incomprehension and ignorance of the environment which makes coping with the disease certainly not easier.

In recent years, 'Brussels' has also become aware of the 'disadvantages' of people with rare diseases. In 2017, this led to the foundation of European Reference Networks (ERNs), in Dutch: Europese Referentie Netwerken. There are 24 ERNs (in 2019), ranging from a network focusing on epilepsy (ERN EpiCare) to a network focusing on organ transplantation in children (ERN TRANSPLANT CHILD). The aim of each network is to centralise all knowledge and experiences of physicians and patients (organisations) of a particular rare disease to make this knowledge and experiences available to other physicians and patients. This should enable all patients with a given rare disease to benefit from the most recent scientific insights about their disease anywhere in Europe and to receive the best possible treatment. Perhaps not at home, but certainly with the help of colleagues from abroad. Less specialised doctors can use the network to consult (European) colleagues who are more specialised in a particular rare disease. This means it’s no longer the patient who has to search for a doctor who understands all ins and outs of his rare disease. Through the network, the local doctor is able to get advise for the doctor who knows best about this particular condition. So, the knowledge and expertise come to the patient, rather than the other way around. It is still a dream of every person affected by a rare disease, that all doctors advise the patient with a rare disease adequately to go to an expert centre.
One of the ERNs is ENDO-ERN, which - as its name suggests - focuses on endocrine diseases. Over 80 centres of expertise from 26 countries are united in ENDO-ERN. This network deals with rare diseases of the adrenal gland, thyroid, pituitary gland and (rare) disorders of the calcium and phosphate balance in the body, genetic disorders of the glucose and insulin balance in the body, disorders caused by genetically determined endocrine tumors, genetically determined obesity and growth disorders and rare disorders of sexual development such as DSD. In the Netherlands 7 hospitals are designated as EXPERTISE centres on one or more rare adrenal, thyroid or pituitary diseases: Amsterdam UMC, Erasmus MC (Rotterdam), LUMC (Leiden), Máxima Medisch Centrum (Veldhoven), Radboudumc (Nijmegen), UMCG (Groningen) and UMCU (Utrecht). In turn, these centres of expertise are part of regional networks in the Netherlands so that every patient can receive state of the art care.

The voice of the patient is also well heard within the ERNs. Patient representatives, the so-called European Patient Advocate Group-representatives, in short ePAGs, make part of every ERN. Of the 14 ePAGs within ENDO-ERN, three originate from the Netherlands: Johan Beun (adrenal disorders), Johan de Graaf (pituitary disorders) and Marika Porrey* (thyroid disorders). In addition to giving a voice to the experiences and needs of patients to doctors and researchers, the ePAGs also contribute to establishing and strengthening contacts between patients and their organisations at a European level. For example, the thyroid cancer working group is currently working hard to make available in several languages an information booklet aimed at children whose mothers are being treated for thyroid cancer. Within the pituitary group, a best clinical practice document for the treatment of congenital hypopituitarianism is being prepared. This will also result in patient educational material in different languages. The stress instructions and emergency cards for people with adrenal disease developed by the Adrenal Society NVACP in collaboration with Adrenal NET can thus be rolled out more effectively throughout Europe.

Thanks to Marten Dooper, the author and with the cooperation of Marika Porrey, Johan de Graaf and Johan G. Beun the co-authors, co-readers.

(*) To our great regret it has become clear with the publication of this article that Marika Porrey (of the SON) can no longer continue her international work. She stopped her work after the summer of 2019.

October 2019.

See also: https://endo-ern.eu/
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.

**JANUARY 2020**
27 to 28 January – Global Summit on Diabetes & Endocrinology, Bangkok, THAILAND

**FEBRUARY 2020**
29 February – Rare Diseases Day, GLOBAL

**MARCH 2020**
5 to 7 March – 17th Biennial Congress of the Asian Association of Endocrine Surgeons, Melbourne, AUSTRALIA
20 to 22 March – 5th Annual World Alliance of Pituitary Organizations Summit, Buenos Aires, ARGENTINA
28 to 31 March – ENDO2020, San Francisco, California, USA

**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
15 to 16 May – The European Conference on Rare Diseases & Orphan Products (ECRD), Stockholm, SWEDEN
23 to 26 May – The 22nd European Congress of Endocrinology, Prague, CZECH REPUBLIC
WEBSITE

Since September 2019 we have been working on updating the website, with our new WordPress hosting company 'Kwaaijongens' in the Netherlands. They gave us useful advice and supported our activities very well, since we were not very 'into' WordPress at the start.

All WAPO patient advocates will receive an email how to login in the 'WAPO Members' section. This closed part on the website will give access to Summit presentations, and additional information. The information has to be updated and needs to grow. If you have interesting news or information to share on the website, please let us know.

Another activity Kwaaijongens' Dominique helped us with, was with setting up a MailChimp account, for sending out the Newsletter. With help of Ashleigh (Australia), the Newsletter looks fine again and is easier to send to all WAPO members and Friends!


WELCOME TO NEW MEMBER ORGANIZATIONS

Acromegaly Ottawa Awareness & Support Network is a Not for Profit Corporation located in Canada’s capital city of Ottawa.

Formed in 2018, we are now 64 members strong with a mission to offer camaraderie and support among acromegaly patients and those who support them and raise awareness of acromegaly through education and advocacy.

Our recent awareness campaign saw us setting up in local malls and providing educational information about acromegaly to shoppers and people who passed by. It was considered a great success as measured by the more than 100 people who received our information. We have plans to incorporate more of this activity in the next year and add local health fairs to our outreach strategy.

Find out more about us at:
www.acromegalyottawa.com
https://www.facebook.com/acromegalyottawa/

Dainne Sauve, December 2019.
The Norwegian Addison Association (MAF) MAF was founded on August 11, 1989. It is a national association organizing people with Addison’s disease, acromegaly, Cushing’s syndrome, hypopituitarism and congenital adrenal hyperplasia (CAH). In 2019 MAF has 848 members across all 17 counties. Add- 48%, Ac _ 9%, Cush-8%, CAH-2%, Hyp-11%, others - 22%. The local 12 county organizations receive yearly funding from MAF and from local bingo games.

The purpose of MAF is to give information and advice about the different diagnoses; to work for equality and inclusion of handicapped individuals and claim recognition of equal rights, worth and capabilities of all people; to facilitate a supporter-relationship (Likepersonsforhold) between members of the association, and to manage a research and development fund.

MAF is working to increase awareness and knowledge in health personnel; to increase awareness and knowledge in next-of kin; for a common universal card with emergency guidelines for the whole of Europe, as well as universal guidelines for health personnel when treating adrenal crises.

Supporter-relationships: MAF works to facilitate supporter-relationships between our members. The purpose is to run an organized transfer of personal experiences between people with different diagnoses and between relatives and family. It is important to provide a supporter available for contact within each county. MAF has both an informational and a guiding purpose. The National Board believes it is important to offer good supporters of both genders and of different ages for the various diagnostic groups represented. There are about 40 active supporters. The supporter arrangement is organized by a board of representatives.

The central board meetings are usually held in Oslo 4 times a year. Every year the central board members visit a County Association at their annual meeting.

How did the ornament get addicted to Christmas?
He was hooked on trees his whole life.

What does the Grinch do with a baseball bat?
Hits a gnome and runs.

What do you call a broke Santa Claus?
Saint-nickel-less.

Why does Scrooge love reindeer so much?
Because every single buck is dear to him!

What do you get when you cross a duck with Santa?
A Christmas quacker.

Why do mummies like Christmas so much?
They're into all the wrapping.

How much did Santa pay for his sleigh?
Nothing. It was on the house!

What do you call an elf wearing ear muffs?
Anything you want. He can’t hear you!

What do you call a blind reindeer?
I have no eye deer.

What do you call an obnoxious reindeer?
Rude-olph.

What do you get when you cross a snowman and a vampire?
Frostbite.

What’s the absolute best Christmas present?
A broken drum—you can’t beat it!

What do reindeers say before they tell you a joke?
This one’s gonna sleigh you!

What’s every parent’s favorite Christmas Carol?
Silent Night.
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WEBSITE
www.wapo.org Please keep checking the WAPO website, which we are changing regularly.

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