

Because Hormones Matter

Working together to raise awareness and promote better endocrine health in Europe

“My diagnosis of acromegaly was completely by chance, thanks to the observation skills by some final year medical students. A few tips I can share: if you know something’s not right, pester your GP; once you’ve reached diagnosis, don’t be afraid – you are not the first and you won’t be the last; seek support via social media and the amazing Pituitary Foundation. You are not alone.”

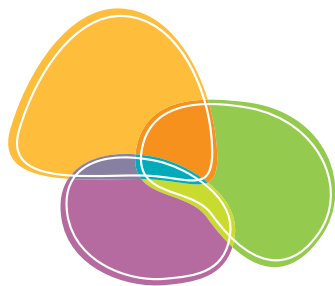
Dan, UK; The Pituitary Foundation



“I was tired, I gained weight and had pain in my body. For years I struggled. I couldn’t get pregnant but the gynaecologist tested my hormones and the thyroid values were very wrong. I started on medication and realized that this started already when I was 16 years old. I didn’t know about the thyroid and what it does for the body. I now have a healthy daughter.”

Lisa, Sweden; Thyroid Federation International

#BecauseHormonesMatter



European Hormone Day

Because Hormones Matter

Hormones Matter!

Hormones and metabolism are highly relevant to public health. Prevalent endocrine diseases such as diabetes, thyroid disorders and obesity have immediate and long-term effects on population health. They also disproportionately affect the most vulnerable population groups in our society.

In addition, there are more than 400 rare endocrine conditions that affect millions of European citizens, but often remain undetected. Adrenal insufficiency, pituitary, bone, metabolic and lipid disorders and endocrine cancers are examples of rare, but

increasingly prevalent endocrine conditions that severely disrupt the lives of patients and their families.

Despite exciting scientific progress and increased awareness in some areas, delayed diagnosis and treatment of (rare) endocrine conditions persist. For example, endocrine cancers such as neuroendocrine tumours and adrenal cancer are mostly detected at a late stage when treatment options have narrowed.

To address these challenges, the European endocrine community must work with national and European decision-makers towards better endocrine health in Europe.

Raising awareness of endocrine conditions should be a top priority, given that many remain unknown to both decision-makers and the public. Better awareness can improve diagnosis and treatment, reduce stigma by creating a better understanding of the symptoms and impact of different conditions, and attract more research funding.

European Hormone Day is an opportunity to bring together the European endocrine community to raise awareness for endocrine health and disease. Only by combining our efforts can we create the necessary momentum to place hormones in the eye of national and European decision-makers as well as the general public.

But European Hormone Day doesn't stand alone: there are many other worldwide or European awareness initiatives that deserve our undivided attention. You'll find many of these listed on the calendar on the following pages, along with patient testimonials that emphasise the importance of awareness-raising activities. This is not an exhaustive list, but we hope it will be a useful resource to focus our combined efforts over the coming year.

We encourage the European endocrine community and partner organisations to join forces under the banner of #BecauseHormonesMatter, and use these initiatives to raise the profile of endocrine health and disease in Europe.

We are grateful to the ESE Affiliated Patient Advocacy Group community for their support in bringing the information provided in this publication together.

Only together can we be successful in creating a better future for patients affected by endocrine diseases, and improving overall endocrine health in the population at large.

Martin Reincke

Chair of the ESE Foundation Board

Jérôme Bertherat

President of the European Society of Endocrinology



“I am 18 years old and have attended over 1,000 appointments with health and allied health professionals. While I am grateful for all the support I have received, life would be easier for me if there was more understanding about Prader-Willi syndrome among professionals and the wider community.”

Louis, Ireland; International Prader-Willi Syndrome Organisation



“As patients with Adrenal Cancer (ACC), we both struggled a few years with multiple hormonal excesses before getting the right diagnosis, as ACC is unknown by most doctors.

ACC patients need to find an expert medical team quickly considering how deadly this neuroendocrine cancer is. Information to doctors AND patients is key to saving lives.”

Catherine (USA) and Sandra (France)
Let's Cure ACC Now



“Let us hope that someday soon there will be greater knowledge of and understanding for our disease. It would be so good if we could get better treatment in the emergency ward.”

Gerda, Denmark;
Addison Foreningen I Danmark

“The most difficult things to manage are the change in my appearance and the fatigue. A word of hope: once the words are put on the ailments, everything becomes clearer. Acromegaly is slowly evolving, people are talking about it more and more. You are no longer alone.”

Soraya, France
Association Nationale de l'acromégalie




“Before my diagnosis, I was getting treatment for generalised anxiety disorder. After discovering one of my adrenal glands was producing too much cortisol, everything fell into place. I needed an adrenalectomy, not psychotherapy and antidepressants. My mental wellbeing greatly improved after that surgery.”

Élise, The Netherlands; Bijniervereniging NVACP

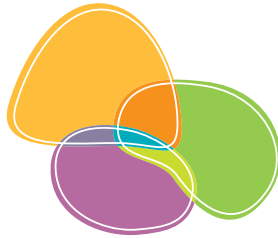


Because Hormones Matter: Annual awareness-raising activities with a link to endocrine health

Let's work together to raise awareness of hormone health.
Lend your support using the hashtag #BecauseHormonesMatter

| JANUARY | FEBRUARY | MARCH | APRIL | MAY | JUNE | JULY | AUGUST | SEPTEMBER | OCTOBER | NOVEMBER | DECEMBER | |
|---------|---|---------------------------|--|--|-----------------------------------|--------------------------------|---|--|--|---|--|--|
| | World Cancer Day (4 Feb) | World Obesity Day (4 Mar) |  <p>European Hormone Day Because Hormones Matter</p> | Prader Willi Syndrome Awareness month (1-31 May) | World Hypopara Day (1 June) | | Phaeo Para Awareness Week (last week of August) | International Children's Growth Awareness Day (20 Sep) | Pituitary Awareness Month (1 – 31 Oct) | World Acromegaly Day (1 Nov) | | |
| | International Childhood Cancer Day (15 Feb) | | | Cushings Awareness Day (8 Apr) | International Nurses Day (12 May) | World Environment Day (5 June) | | | | World MCT8-Allan-Herndon-Dudley Syndrome (AHDS) Day (8 Oct) | World Neuroendocrine Tumor (NET) Cancer Day (10 Nov) | |
| | Rare Disease Day (last day in Feb) | | | World Earth Day (22 Apr) | World Thyroid Day (25 May) | | | | | World Menopause Day (18 Oct) | World Diabetes Day (14 Nov) | |
| | | | | Addison's Disease Day (29 May) | | | | | Global Iodine Deficiency Prevention Day (21 Oct) | | | |
| | | | | EU Green Week* | | | | | | | | |

* Exact dates vary each year



European Hormone Day

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Raising awareness of hormone health is a team effort. We would like to thank the following patient organisations from ESE's Patient Advocacy Group Membership and the other Groups for their support in developing this leaflet – and for their hard work in advocating for people affected by endocrine-related conditions.

| Name | Website |
|--|--|
| Acromégales pas Seulement | www.acromegalie-asso.org |
| Addison's Disease Self Help Group UK | www.addisonsdisease.org.uk |
| AdrenalNET (BijnierNET) | www.bijniernet.nl |
| AGS- Eltern- und Patienteninitiative e.V. | www.ags-initiative.de |
| AIPAd Italy | www.morbodiaddison.org |
| ANDO Portugal | www.andoportugal.org |
| Association for Multiple Endocrine Neoplasia Disorders (AMEND) | www.amend.org.uk |
| British Thyroid Foundation | www.btf-thyroid.org |
| Bundesverband Schilddrüsenkrebs - Ohne Schilddrüse leben e.V. | www.sd-krebs.de |
| CAH Support Group (UK) | www.livingwithcah.com |
| Cushing's Support & Research Foundation | www.csrff.net |
| Danish Addison Society | www.addison.dk |
| European MEN Alliance e.V. (EMENA) | www.emena.eu |
| hypoPARA NORGE | www.hypopara.no |
| Hypoparathyroidisme France | www.hypopara.fr |
| International Prader-Willi Syndrome Organisation (IPWSO) | www.ipwso.org |
| Let's Cure ACC | www.lets cureacc.com |
| Nederlandse Hypofyse Stichting (Dutch Pituitary Foundation) | www.hypofyse.nl |
| Netzwerk Hypophysen - und Nebennierenerkrankungen e.V. | www.glandula-online.de |
| Parathyroid UK | www.parathyroiduk.org |
| Pituitary Foundation UK | www.pituitary.org.uk |
| SOD Italia | www.soditalia.it |
| The Dutch Adrenal Society NVACP | www.bijniervereniging-nvacp.nl |
| Thyroid Federation International | www.thyroid-fed.org |
| Turner Syndrome Support Society UK | www.tss.org.uk |
| Verity PCOS | www.verity-pcos.org.uk |
| Vivre sans Thyroïde | www.forum-thyroïde.net |
| World Alliance of Pituitary Organizations | www.wapo.org |



“As a patient suffering from a rare endocrine tumour disease, I have the privilege to celebrate twice a year: on my birthday in September, and on 10 November when the “zebra” in me celebrates World NET Cancer Day.”

Petra, Germany; European MEN Alliance (EMENA)



“Access to endocrinologists who are sufficiently aware of the intricacies of hypoparathyroidism is a major difficulty. Too often care is haphazard and not backed by other caregiving professions, such as hospital staff and GPs.

This impacts significantly on our quality of life and mental health.”

Ruth, UK; Parathyroid UK



“Lack of knowledge about hypoparathyroidism among doctors leads to stigmatised and delayed treatment.”

Helen, Norway; hypoPARA Norge



“When explaining treatment for adrenal crisis to a medic who is unaware of Addison’s disease, you feel like you’re fighting not to be dismissed. You try to explain without seeming uncooperative. You don’t feel safe at your most vulnerable. Greater awareness and support change the situation from one of fear and desperation, to patient empowerment and education. That means faster, accurate treatment and a better quality of life.”

Philippa, UK;
Addison’s Disease Self-Help Group UK and ROI

About the European Society of Endocrinology

The European Society of Endocrinology (ESE) provides a platform to develop and share leading research and best knowledge in endocrine science and medicine. By uniting and representing every part of the endocrine community, we are working to improve the lives of patients.

Through the 50 National Societies involved with the ESE Council of Affiliated Societies (ECAS) and our partnership with specialist endocrine societies, ESE and its partners jointly represent a community of over 20,000 European endocrinologists.

ESE and its partner societies work to promote knowledge and education in the field of endocrinology to health care professionals, researchers, patients and the general public.

We inform policy makers on health decisions at the highest level through advocacy efforts across Europe. To find out more please visit www.eese-hormones.org.

About the European Hormone and Metabolism Foundation

The overarching aim of the European Hormone and Metabolism Foundation – Foundation of the European Society of Endocrinology (ESE Foundation) is for public benefit.

The European Hormone and Metabolism Foundation is a non-profit organisation dedicated to improving human health. By focusing on people with endocrine disorders, the ESE Foundation's mission is to promote endocrine health, address endocrine disease, and improve patient care. Our goal is to devote to hormone and metabolic health. To ensure the best possible quality of life, our mission is to raise public and political awareness of hormone and metabolic health and disease, as well as research, policies, and care.

Follow the ESE Foundation at www.eese-foundation.org.

#BecauseHormonesMatter

