EASO ECPO European Coalition for People living with Obesity

ECPO History, and the 'Why the patient perspective and engagement is important'

ECPO HISTORY

EASO Patient Council

- Patient council developed in 2013 as a EASO working Group ‘EASO Patient Council’
- Patient Council consisted of 16 council members from 13 countries
- Many achievements over the years but recognised the need to become an independent Patient umbrela organisation.
- Launched as ‘ECPO’ in 2019 at ECO2019 with 22 countries and 30 advocates
- Incorporated in Ireland
- Currently 51 council members across 31 countries
- 8 board members, 7 executive committee members
- 10 committees led by Patient Council members voluntarily

Launch & Incorporation as ECPO

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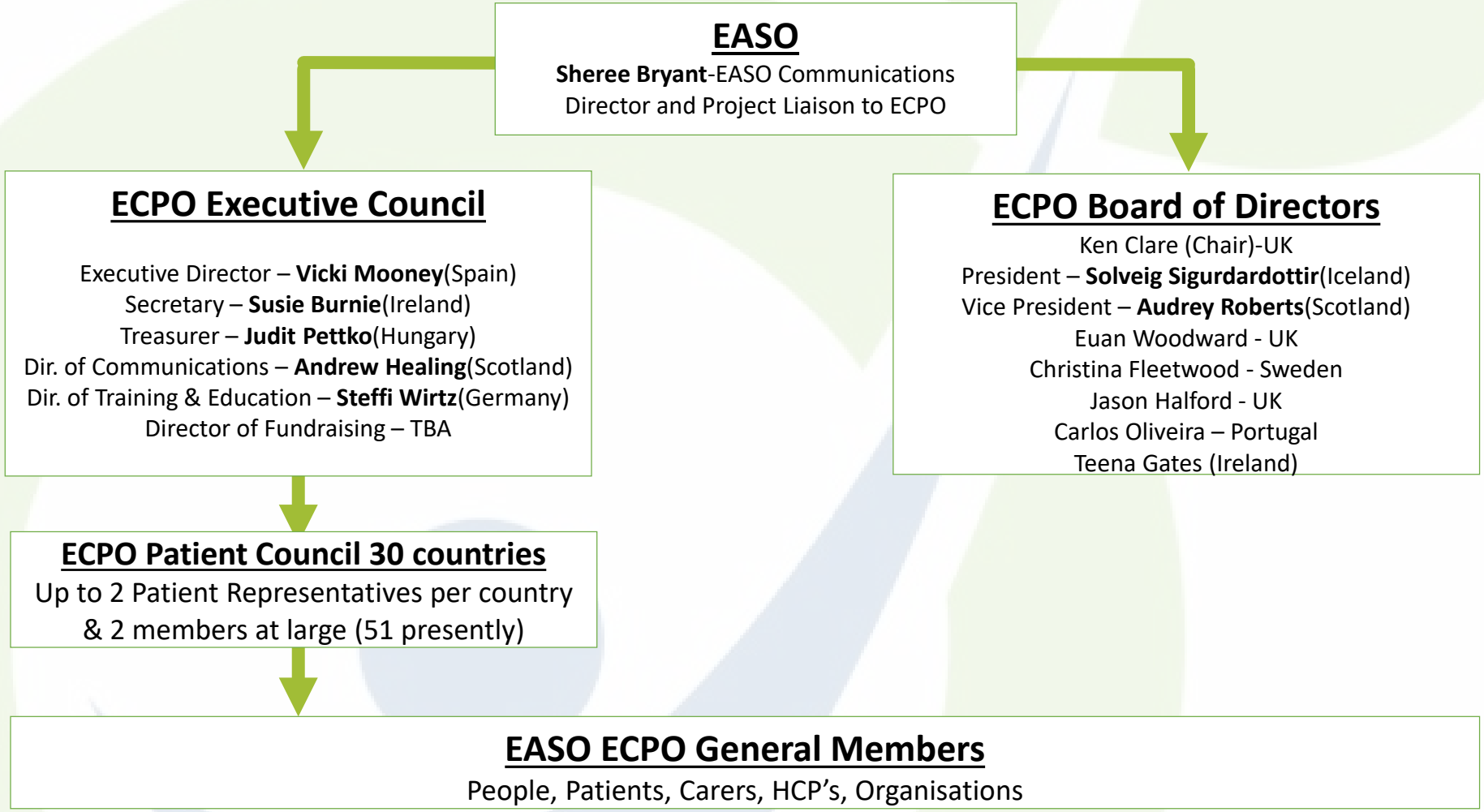
ECPO Organisational Structure



EASO ECPO European Coalition for People living with Obesity

ECPO Mission Statement

Building a vibrant community to educate and empower those individuals who are living with and those who are affected by the chronic disease of obesity within Europe.

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ECPO Vision Statement

The ECPO is a patient led, managed and run organisation working collectively to be the authoritative patient voice in Europe with respect to evidence-based approaches for obesity prevention, treatment and policy, by facilitating knowledge exchange, research and educating people who live with and are affected by the chronic disease of obesity.

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5 Year Strategic Goals for ECPO as an organization

Capacity

A professional secretariat, coordinating well-funded but independent activities

A leading, respected, trusted European organizations that gives people living with obesity a voice

grown the organisation, strengthened the national organizations

Brand recognition

Skills development for ECPO members

Education

A trusted resource for patients, the media, HCPs, and the public

Website, tools, resources in all languages

Strong media connections and presence, and visible annual activities

Advocacy

Regarded as the relevant advocacy organisation in Europe

PwOs influencing health, education, social policies across Europe

Access

Active partnerships with multiple stakeholders to increase access to care

PwOs participating in education to HCPs

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Measures of Success

- Obesity recognized and treated as a chronic disease in European countries
- Expansion of patient representatives and national organizations in Europe
- Increased participation of patients in HCP conferences, policy events, and media outreach
- Increased media impressions of ECPO
- Ongoing development and expansion of ECPO tools, resources, programs and education activities
- Overall satisfaction of ECPO members and national organizations with support and collaborative activities
- Increased stakeholder awareness of ECPO, its purpose, and activities
- Increased satisfaction from ECPO advocates speaking engagements
- Increased number of ECPO public events

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How does ECPO provide value to individual country associations/members?

Trusted knowledge, resource, information hub

Offer support and collaboration to strengthen European activities and messaging

Share resources to raise awareness about obesity as a chronic disease

Provide training and education sessions to patient advocates, HPCs and policy makers

Unite and empower the voices of patients living with obesity

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How does ECPO provide value to partners?

ECPO can support national advocacy efforts

Opportunity to coordinate consistent media responses

Alignment of shared goals and objectives

Provide support (common knowledge, sending speakers, etc.)

Celebrate best practices at the national level

ECPO can provide materials such as digital platforms, lecture materials, booklets

Create strong community of people living with obesity

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HOW DO WE AS PATIENTS DO ALL OF THIS?

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European Congress on Obesity

Where it all started!

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Total involvement of 45 patients across 27 countries in 2020 virtually

Belgium
Sweden
Austria
Germany
Slovakia
Czech rep
Iceland
Switzerland
Kenya
Northern Ireland
Norway
Scotland
Malta
Caribbean
Ireland
England
Italy
UAE
Africa
Spain
France
Portugal
Denmark
Poland
Finland
Canada
USA

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ECO

- Patient advocates opening and closing the congress alongside EASO
- Patient Advocates co-chairing sessions
- Patient advocates speaking at sessions
- European Image bank gallery at the congress
- High social media presence from ECPO

TRAINING

ENS2022

- 38 Patient Advocates
- 15 countries represented
- Simultaneous translation in 9 languages
- iPad and headset for each advocate
- Platform for all trainings, presentations and sharing of information.
- WOD planning & filming in 10 languages
- Mapping of Patient landscape across Europe
- Negotiating, Media & presenting training
- Science of Obesity presented
- EASO & ECPO relationship
- Patient voice identifying what patients need across Europe

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Education

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CAMPAIGNING TOGETHER

We are People/Patients who live with Obesity

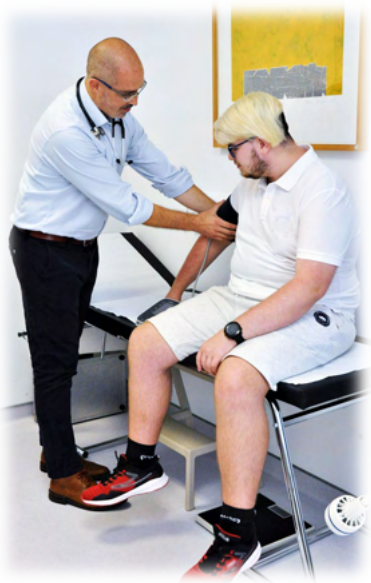
Our weight does not define us.

We are mother's, father's, daughters, brothers, Students, Policy Makers, MEP's, Swimming Instructors, Public Speakers...

We are People First.

And we have a disease called Obesity.

#PeopleFirst Campaign



- Live ECPO broadcast events on the ECPO website.
- Launch of the ECPO videos on ‘Living with Obesity’ in various European languages.
- Launch of first European Image bank - www.ECPOmedia.org
- Sharing of educational infographics on Obesity in various European languages.
- Launch of ECPO & URHealth4Life Magazine.
- Grants to support national activities
- Call to action for People-First Language and Images globally.

People First/Living With Obesity Campaign

Infographics

EUROPE'S OBESITY PROBLEM TAKES ON NEW URGENCY

LIVING WITH OBESITY MEANS BEING PART OF A VULNERABLE POPULATION

From 47% in 1990, the number of people living with obesity in the EU has risen to 60% in 2016. Living with obesity can lead to more than 230 different complications. Many people are asking how the EU will support and assist people.

WHAT DOES THIS MEAN FOR OUR PATIENT COMMUNITY?

Studies from China, the United States, France, Belgium and Sweden have found that people with obesity who contract COVID-19 are at a greater risk of being hospitalised and needing critical care. Living with obesity seems to be a more concerning factor than pulmonary disease or cancer.

WHAT SHOULD THE EU BE DOING TO HELP PEOPLE LIVING WITH OBESITY?

The World Health Organisation recognises obesity as a chronic disease. Jacqueline Bowman-Busato, the EU Policy Lead at the European Association for the Study of Obesity, believes that the EU should be doing the same. She also asserts that there is "more to obesity management than healthy eating", including hormonal, environmental and psychological factors.

WHAT ARE THE NEXT STEPS?

The ECPO and other collaborating national organisations believe, and agree with Bowman-Buscado, that once the EU has acknowledged obesity as a chronic disease, it could produce a framework to "harmonize obesity response plans in different member countries and help strengthen obesity centres of management". In addition to this, we believe that to deal with obesity properly, "that means expanding and extending the narrative."

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HTTPS://WWW.POLITICO.EU/ARTICLE/EUROPE-OBESITY-PROBLEM-CORONAVIRUS/

www.eurobesity.org

CALL FOR OBESITY TO BE INCLUDED AS A NON-COMMUNICABLE DISEASE IN THE EU4HEALTH PROGRAMME

WHAT DOES THIS MEAN?

Six MEPs have joined 38 different organisations (all major health policy stakeholders in Europe) in calling on the EU4Health programme to recognise that positioning obesity as a risk factor on par with tobacco and alcohol fuels the societal idea that obesity is a lifestyle choice

WHY ARE WE CONCERNED?

The European Commission correctly categorised obesity as a medical vulnerability and the latest Foresight Report in September 2020 specifically prioritises obesity alongside cancer as the two non-communicable diseases that should take top priority in the coming period

IS THIS A NEW IDEA?

Actually, no. The World Health Organisation has long since recognised obesity as a disease. Portugal, Turkey, the Netherlands, Italy and Germany also recognise it as a chronic disease

WHAT DIFFERENCE WILL IT MAKE?

Treating obesity as a non-communicable disease saves lives. It will also play an important role in the overall recovery of the EU as part of our new reality after COVID-19

ALIGNING WITH THE SCIENCE

We simply ask that the European Council aligns with the European Commission, The European Parliament and the scientific community by categorising obesity as a chronic, relapsing disease

https://woday.eu/news/meps-call-for-obesity-to-be-included-as-a-non-communicable-disease-in-the-eu4health-programme/

#EU4HEALTH
#FOLLOWTHESCIENCE

THE STIGMA OF LIVING WITH OBESITY

HOW COMMON IS WEIGHT BIAS?

Studies conducted by the Rudd Centre for Food Policy and Obesity found that 54% of adults with obesity face stigma in the workplace, while 64% of adults with obesity reported experiencing weight bias from healthcare professionals

WHAT IS THE EFFECT OF STIGMA?

Stigma impacts health policies, limiting access to evidence-based obesity management and support. For people with obesity, weight stigma can also have negative effects on friends and family, in schools and in employment.

INTERNALISED WEIGHT BIAS

As a person with obesity, no matter where you go or who you meet- stereotypes and misconceptions are always there, sometimes openly, sometimes in the background. You begin to believe that the negative beliefs associated with the disease of obesity are true.

WHAT HAPPENS TO PEOPLE WHEN THEY EXPERIENCE STIGMA?

Stigma and internalised weight bias can lead to a variety of emotional, behavioural, social and physiological effects. Eating disorders, suicidal thoughts and acts and anxiety can be triggered by these experiences.

WHAT ACTION CAN BE TAKEN?

Join our People First Campaign Day on Wednesday 21st October 2020. We are highlighting the importance of people first language (ie. "person with obesity" rather than "obese person". We are aiming to be seen as not defined by our illness, but rather living with it. Use our hashtag #LivingWithObesity to join the discussion!

ECPO PEOPLE FIRST CAMPAIGN DAY, WEDNESDAY OCTOBER 21st

#LIVINGWITHOBESITY

WHAT CAUSES OBESITY?

ONE FACTOR IS GENETICS

UP TO 80% OF OUR BMI IS DETERMINED BY GENES

Our weight is governed by certain genes, and if you carry a high number of these genes you are 15 times more likely to live with obesity than someone without these genes. Studies of identical twins raised apart show that even when they live in different environments, they will have similar BMI.

OUR WEIGHT CAN BE DETERMINED BEFORE WE ARE BORN

Babies born to mothers living with obesity are at a higher risk to develop obesity. Weight changes in mothers and fathers contribute to the genetic aspect of weight; weight is also affected by the interaction between genes and environment.

OUR REACTION TO DIETS ALSO HAS A GENETIC COMPONENT

How bodies respond to raised or lowered calorie intake varies from person to person. Even our responses to television adverts for foods can be influenced by our genetics.

OBESITY IS A DISEASE

Obesity is a chronic, relapsing disease. It can negatively impact physical and mental health, as well as overall quality of life. Obesity has many causes and is about a lot more than exercise or food.

WE NEED TO DO MORE

Not only is it important to raise awareness of obesity as a chronic disease, but we must also remove the stigma around living with obesity. People living with obesity deserve the same compassion and dignity offered to anyone who faces a chronic illness.

ECPO PEOPLE FIRST CAMPAIGN DAY, WEDNESDAY OCTOBER 21st

#LIVINGWITHOBESITY

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LIFE STORY

Dealing with Covid-19

BY MAGDA GAJDA
ECPO REPRESENTATIVE, POLAND

Magdalena Gajda - journalist (specialization: health and society), specialist in PR, CSR, social communication and storytelling. The Ombudsman for the Rights of People with Obesity Disease in Poland, the founder and president of the Foundation for People with Obesity Disease and a member of the European Coalition for People Living with Obesity.

My name is Magdalena. I come from Poland. I am a person with Obesity disease.

In October, I was infected with the Coronavirus and fell ill with COVID-19. Here is a short diary of my illness ...

October 14 – Wednesday

I woke up at 06.00 am. I have slept well, but I am weak. For about 1-2 weeks I have been slowly losing my will to live. I force myself to wash, dress, work, talk to people every day. I wonder if this is maybe depression? This year is more difficult for me than others. My mother died in June. I have been living in constant fear since March. Will I get the Coronavirus? I have obesity disease. I am at the highest risk.

In the afternoon I feel very bad, but I put on a mask and gloves and leave the house. I have to deal with some important issues and do some shopping.

When I come back by tram, I feel very faint. With difficulty I come home. My hands shake as I put the key in the lock. I lie down on the couch with relief. My head hurts and is spinning. I feel neither cold nor warm. My back also hurts. I have a dry cough and a low fever. "I must have caught a cold," I think to myself. "Hot shower, hot tea with raspberries, warm bed, plenty of sleep and I will feel better tomorrow" - I console myself.

October 14-15 - the night from Wednesday to Thursday

I'm not sleeping. I feel like I'm suspended between being awake and sleep. The fever increases, and my temperature now is almost 39 degrees Celsius. I'm sweating, my muscles hurt, so I take medication to lower my fever. I then fall asleep.

October 15 - Thursday

I wake up before 7.00 a.m. The fever is still high, so I call my health clinic. I ask them for a quick consultation with a doctor. I describe to them my symptoms. It could be the flu, but it could also be COVID-19. I am not panicking, but I am afraid, and need help. I also need a referral for a free Coronavirus test.

In the Polish health care system, only my family doctor can issue them.

The front desk lady, at the health clinic says it is not possible to see a doctor. During a pandemic, doctors in Poland provide advice by telephone.

The nearest possible date for telephone medical advice reimbursed by your insurance is ... October 30, but if I want private advice then I have to pay for it, and that will take place on ... 23 October. I'm nervous and I ask what should I do if I feel worse and worse. The lady recommends that I then call the ambulance ...

I call my sister Anna. I ask her not to come over to me just in case. Anna is afraid for me. I live alone. What if something happens to me at night and I don't have the strength to call for help?

Fear is the worst with COVID-19. You don't know this disease, so you don't know what to expect. You are afraid that you will die alone, gasping for every breath.

October 16-18 - from Friday to Sunday

The fever goes up and down. My muscles and head still hurt, and I still have a cough. Fortunately, I can breathe. I do not want to eat. I drink a lot, mostly warm tea with lemon. I remember this important rule: if you cannot eat - drink plenty of fluids so as not to dehydrate your body.

I feel very weak. Just getting out of bed and going to the bathroom is a big effort.

I also have trouble concentrating, I can't read books or watch TV, and I am sleeping a lot.

On Sunday evening my friend Katarzyna calls me. She found out by accident that I felt unwell.

My friend is an internist. He also deals with COVID-19 patients. Katarzyna gives me a private medical consultation - she recommends medications to help me cough and moisturise my throat as well as medications to reduce fever. According to Katarzyna, her opinion is that I have COVID-19.

October 19 - Monday

My sister buys medication for me, and leaves it outside my apartment.

October 21 - Wednesday

The fever has finally dropped. I am weakened, but I feel better. The cough is also getting better. - Maybe I was unnecessarily scared? I wonder, but ... I brush my teeth and ... I don't feel the minty taste and smell of the toothpaste. I'm doing a test. I squirt my perfume right down my nose. I don't smell anything ... I put chili peppers on my tongue. I don't feel anything ... I call Katarzyna quickly. Katarzyna is already sure: 100 percent I have COVID-19...

My name is Magdalena. This is my COVID-19 story. But this is also the story of thousands of people around the world who do not know when and how they contracted the Coronavirus.

This is the story of people who have had COVID-19 with mild symptoms and did not need to be hospitalized. This is also the story of people who, in overburdened health care systems, did not receive official medical care and had to self-medicate.

I was lucky - I had a bariatric surgery 10 years ago and am now slightly overweight. The more advanced the obesity disease, the more severe the symptoms of COVID-19. I was lucky because I had family and friends who helped me.

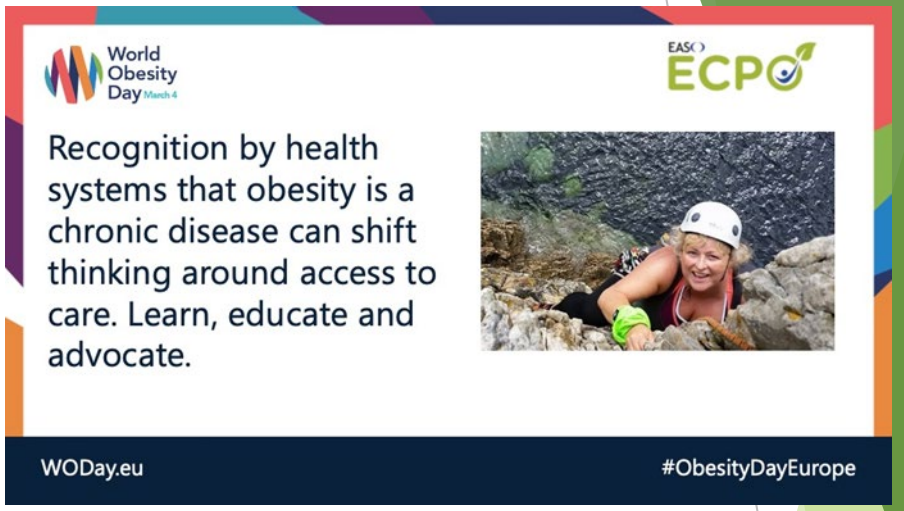
Unfortunately, many people living with obesity are not so lucky...

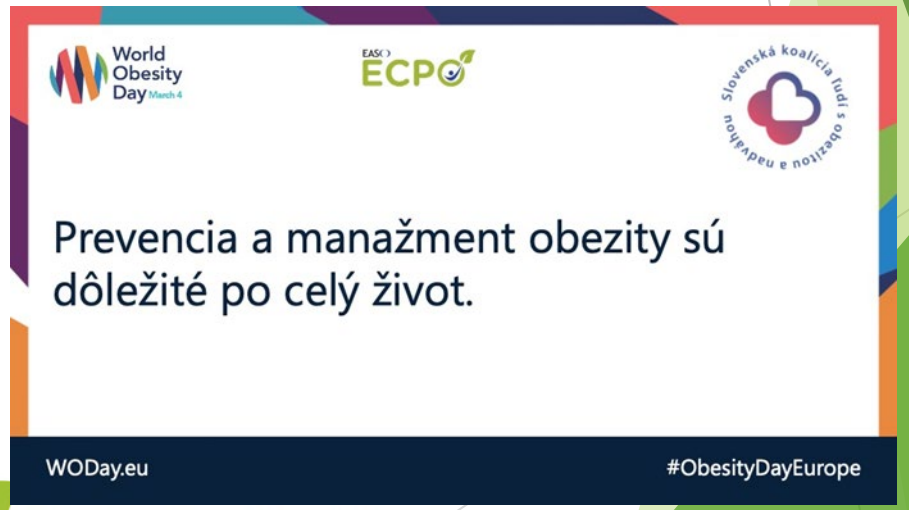
It's November. I feel better. I can smell and taste again. But some post COVID-19 symptoms remain. I get tired quickly, I often have a headache, I have attacks of breathlessness that I haven't had before. I am tired of insomnia. But I leave home, work and help other sick people.

Because the pandemic is a great test of our humanity. We must shut ourselves up at home, but let's not close ourselves off from other people. Stay at home. But also become human.

ECPO Magazine

World Obesity Day





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The #WorldObesityDay Influencers

Top 10 Influential	Prolific Tweeters	Highest Impressions
@ECPObesity 100	@ECPObesity 357	@WHO 53.7M
@EASOobesity 100	@ptmariosilva 215	@UN 30.1M
@ObesityDayEU 92	@solveigsig 203	@aajtak 16.4M
@WorldObesityDay 83	@JMBernK 200	@TimesNow 10.2M
@WorldObesity 78	@T2DMBot 123	@UNICEF 9.1M
@ObesityAction 69	@globalhealthbot 118	@IndianExpress 4.1M
@ObesityCan 69	@susieb16 112	@JagranNews 3.9M
@ObesitySociety 67	@AcSDeV1 102	@indiatvnews 3.9M
@WHO 65	@DianeCharleton 97	@UNICEFIndia 3.1M
@ICPObesity 63	@ICPObesity 96	@UNarabic 2.9M
Tweet	Tweet	Tweet

Top 10 Influencers is determined by the SymplurRank algorithm.

The Numbers

226.540M Impressions

15,119 Tweets

7,074 Participants

79 Avg Tweets/Hour

2 Avg Tweets/Participant

Tweet

Twitter data from the #WorldObesityDay hashtag from Fri, February 25th 2022, 11:55PM to Sun, March 6th 2022, 12:05AM (Europe/Dublin) – Symplur.

SYMPLUR
PART OF REAL CHEMISTRY

ADVOCACY

EASO

INTRODUCTION TO ADVOCACY

1. What Is Advocacy And Why Is It So Important?
2. What Can You Achieve?
3. How Does The Patient Advocate Play A Role
4. Advocacy In 6 Simple Steps

INTRODUCTION TO ADVOCACY

Find out why patient advocacy is so important and how to use this toolkit to create and manage your own successful advocacy campaign

1. WHAT IS ADVOCACY AND WHY IS IT SO IMPORTANT?

In its simplest form advocacy is when a person or organisation / body publicly supports and champions a cause.

Patient advocacy is therefore about making a change for the people you represent by building relationships with other individuals or organisations, with the aims of:

- Influencing policy makers, regulators and other players who can bring about change
- Influencing decisions within political, economic, social, health or educational systems
- Gaining public support for a cause

The key to a successful campaign is to gather widespread national and regional support, e.g. through

- Collaborating with other organisations
- Encouraging community activity (including marches)
- Fundraising
- Talking with ministers and / or government
- Liaising with the media

2. WHAT CAN YOU ACHIEVE?

Your advocacy campaign could make beneficial changes in many ways, such as:

- persuading policymakers to change policies around things like reimbursement of obesity treatments, recognition of obesity as a disease, introducing legislation to protect against weight bias and stigma.
- creating public awareness and support for an issue (for example the health benefits of weight loss, the medical complications of obesity), and can bring together diverse stakeholders around a single issue.

3. HOW DOES THE PATIENT ADVOCATE PLAY A ROLE

Patient advocacy is a critical part of influencing change. As someone living with obesity, sharing your story can be an incredibly powerful part of an advocacy campaign. It brings personal experiences to the attention of decision makers and puts a "human face" on a complex disease. Your real story will:

- Stir EMOTION in those listening, that would otherwise not happen, adding real impact
- Interest the MEDIA and thereby help change public opinion (increasing knowledge and reducing stigma)
- Make you a role model for OTHERS AFFECTED
- Put a FACE and STORY to a cause
- Add CREDIBILITY through your real experience (no one else knows what it is like)

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Advocacy

Interactive Patient Advocacy Programme (IPAP)

- Using the EASO ECPO Patient Advocacy Handbook 2021 edition.
- Translation of Handbook to various languages
- IPAP April - June
- 8 sessions using the advocacy handbook
- Moderated by Sophie Millar & Vicki Mooney with guest facilitators from EASO & OPEN
- Offered to all patient council members
- Hosted on ECPO Training HUB

EASO

EXAMPLE ADVOCACY SUCCESS STORIES

Case Study 3

ITALY: CHARTER OF HUMAN RIGHTS FOR PEOPLE WITH OBESITY AND OFFICIAL PARLIAMENTARY RECOGNITION OF OBESITY AS A REAL DISEASE

Background

The rights of people with obesity should be the same as the human and social rights of people without obesity.
The multi-stakeholder collaborative efforts in Italy include a Charter of Human Rights to increase awareness and dialogue with government institutions to ensure the protection of health and treatment of people living with obesity.

Aims of the campaign

- To guarantee people with obesity have consistent and full access to information, assistance and innovative treatments throughout the country
- To support people with obesity and their families to overcome obstacles, prejudices, low confidence and discrimination
- Increase awareness in government institutions of the urgency for recognising obesity as a debilitating disease, which needs specific legislative and regulatory support

Key Activities

- Meetings were organised with scientific societies, politicians and associations for patients and active citizenship
- A network involving scientific societies and political associations for patients and citizens (OPEN Italy) was created to establish strategies for recognising obesity as a social and economic disease and problem
- A motion was submitted in parliament to commit the government to 1) recognise obesity as a real disease, which requires dedicated attention and resources, and 2) guarantee a strategy for effective action for prevention and care

Outcomes

- Publication of the Italian Obesity Barometer report containing official data on obesity at the economic, political, social and epidemiological level
- The motion, presented at the Chamber of Deputies, was voted unanimously 458/458 by all parliamentary groups as a demonstration of a common commitment of all political forces in the fight against obesity
- As a result of the motion, Government is committed to implement a dedicated and appropriately financed national plan for the prevention and fight against obesity and to include the disease in the LEAs (Essential levels of assistance)
- An open letter was presented to the Minister of Health and to the various government decision makers calling for the protection of people with obesity and explaining how they are more vulnerable in the phases of the COVID-19 emergency

For further information:

https://www.amiciobesi.it/
https://www.facebook.com/amiciobesi

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Diana Castillo. Patient Advocate: castilloserrano.dianamaria@gmail.com or diana@eurobesity.org

EASO ECPO

Toolkits & Grants Supporting National organisations

- World Obesity Day financial support of €25,000 across 11 national organisations to create, and translate ECPO WOD materials, and support their agreed national activities
- New organisation start up support Luxembourg, Netherlands
- **Upcoming New Patient Orgs 2022 Iceland, Turkey, Israel**
- Further Development of Organisation Hungary & UK
- Mentorship Programme for patient organisations
- Infrastructure development for new patient organisations
- Advocacy handbook education and training for policy & campaigning

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