

**ECPO History, and the ‘Why
the patient perspective and
engagement is important’**

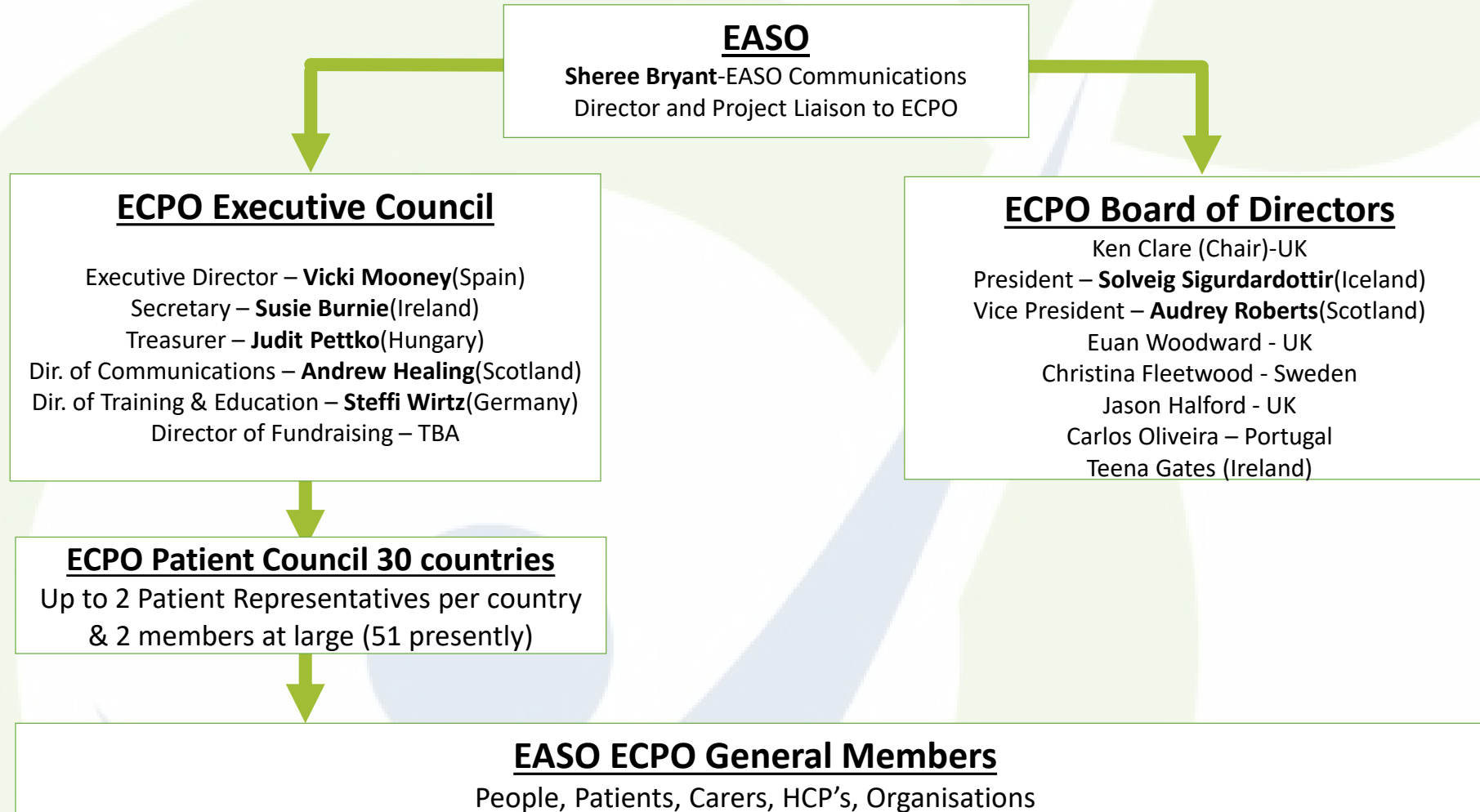
EASO Patient Council

ECPO HISTORY

- ▶ 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 umbrella 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

ECPO Organisational Structure



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.

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.

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

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



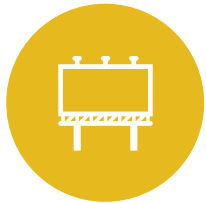
Increased media impressions of ECPO



Ongoing development and expansion of ECPO tools, resources, programs and education activities



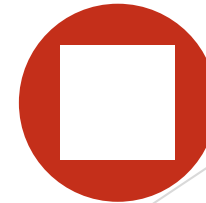
Overall satisfaction of ECPO members and national organizations with support and collaborative activities



Increased stakeholder awareness of ECPO, its purpose, and activities



Increased satisfaction from ECPO advocates speaking engagements



Increased number of ECPO public events

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

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

HOW DO WE AS PATIENTS DO ALL OF THIS?

European Congress on Obesity

Where it all started!



European Coalition
for People living
with Obesity

Topic Session: Drugs and Surgeries for Obesity Management – Mechanism Action



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



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

Moving
Influence.



Educated
Champion

Shannon
Journalist,
Foundation

engaging the media on
responsible reporting of
obesity

Webinar 1.mp4

Start conversation

Webinar 1: How to optimise Personal Time Management



beproductive.ie



Education



People-First Language for Obesity

Labelling people as 'obese' has a very negative impact...

- It creates negative feelings towards that individual
- It affects how likely they are to seek medical care
- It perpetuates weight bias and stigma
- It causes discrimination
- It influences how that person feels about their condition and themselves

...it needs to end.

People-first language has been widely adopted for most chronic diseases and disabilities – but not obesity.

We believe it's time to make a change.

Are you People-First? We are.

Help eradicate weight bias and stigma. Help strengthen respect and dignity for people with obesity.

**PICK UP YOUR RIBBON AND
SHOW YOUR SUPPORT**

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-Busato, 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.**"



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



ECPO

CZY WIESZ, ŻE NASZE ORGANIZMY BRONIĄ SIĘ PRZED UTRATĄ WAGI?



CZŁOWIEK ROZWIJAŁ SIĘ, ABY UTRZYMYWAĆ MASĘ CIAŁA

Przez większą część istnienia ludzkości walczylimy o jedzenie. Oznacza to, że na przestrzeni historii ludzkości nasze organizmy preferowały przybieranie na wadze, a nie jej utratę. Nasze organizmy wypracowały mechanizmy obronne, które utrudniają utratę wagi.

ZNACZĄCA UTRATA MASY CIAŁA ZMIENIA NASZĄ GOSPODARKĘ HORMONALNĄ

Gdy tracimy na wadze, nasza gospodarka hormonalna zmienia się i wywołuje jest większe poczucie głodu oraz mniejsza satysfakcja z jedzenia. Nasz organizm przestawia się na tryb oszczędzania energii i może nawet zmniejszyć swoją temperaturę, aby zapobiec dalszemu traceniu na wadze.



UTRACONA WAGA ZWYKLE JEST ODZYSKIWANA

80% ludzi, którzy stracili 5% masy ciała odzyskuje ją w ciągu pięciu lat. Większość badań analizujących wpływ diety i ćwiczeń fizycznych wskazuje, że każda utracona w ich efekcie waga wraca w ciągu 4-7 lat.

„NOWA NORMALNOŚĆ”

Ekspert w zakresie otyłości, dr Arya Sharma z Obesity Canada, uważa, że gdy zwiększamy swoją masę ciała, nasze organizmy będą bronić wyższej wagi i traktować ją jako „nową normalność”. W ramach tego procesu możemy nawet mieć ochotę na bardziej kaloryczną żywność... „Lubię porównywać to do naciągania gumowej taśmy. Tracisz na wadze... naciągasz tę gumową taśmę... w chwili, gdy odpuszczasz, natychmiast do Ciebie wraca”



CZY USUNIĘCIE PIĘTNA POMAGA?

Otyłość to przewlekła choroba, która ma więcej przyczyn, niż nam się wydaje. Mimo że nawet 80% przypadków otyłości ma podłoże genetyczne, ludzie z otyłością często czują się osobiście odpowiedzialni za to, ile ważą. Jak możesz pomóc? Aby uzyskać więcej informacji, odwiedź naszą witrynę internetową.

DZIEŃ KAMPANII
ECPO PEOPLE
FIRST – ŚRODA,
21 PAŹDZIERNIKA



#LIVINGWITHOBESITY



ECPO

COSA CAUSA L'OBESITÀ?

UN FATTORE È LA GENETICA



FINO ALL'80% DEL NOSTRO BMI È DETERMINATO DAI GENI

Il nostro peso è regolato da determinati geni e se si ha un elevato numero di questi geni, la possibilità di vivere con l'obesità è 15 volte superiore rispetto alle altre persone. Gli studi sui gemelli omozigoti cresciuti separatamente hanno mostrato che anche vivendo in ambienti diversi, presentavano un BMI simile.

IL NOSTRO PESO PUÒ ESSERE DETERMINATO PRIMA DELLA NASCITA

I bambini di madri che vivono con l'obesità presentano un rischio più elevato di svilupparla. I cambiamenti di peso dei genitori contribuiscono alla componente genetica del peso; il peso è anche condizionato dalla interazione tra geni e ambiente.



ANCHE LA NOSTRA RISPOSTA ALLE DIETE HA UNA COMPONENTE GENETICA

Il modo in cui il corpo di una persona reagisce a una maggiore o minore assunzione calorica varia da persona a persona. Anche le nostre reazioni alla pubblicità televisiva degli alimenti possono essere influenzate dalla genetica.

L'OBESITÀ È UNA MALATTIA

L'obesità è una patologia cronica e recidivante. Può avere un impatto negativo sulla salute fisica, mentale e sulla qualità della vita in generale. L'obesità ha molte cause e va decisamente oltre il mero esercizio fisico o l'alimentazione.



DOBBIAMO FARE DI PIÙ

Non solo è importante accrescere la consapevolezza dell'obesità come patologia cronica, ma dobbiamo combattere ed eliminare lo stigma che colpisce chi convive con l'obesità. Queste persone meritano la stessa comprensione e la stessa dignità offerte a chiunque affronti una patologia cronica.

GIORNATA EUROPEA
DELLA CAMPAGNA
"PRIMA LE PERSONE"
MERCOLEDÌ
21 OTTOBRE



#LIVINGWITHOBESITY



ECPO

LA STIGMATISATION AUTOUR DE L'OBÉSITÉ



LE POIDS FAIT-IL SOUVENT L'OBJET DE PRÉJUGÉS ?

Des études menées par le Rudd Centre for Food Policy and Obesity ont montré que 54 % des adultes obèses sont stigmatisés sur leur lieu de travail, tandis que 64 % des adultes obèses ont déclaré avoir été victimes de préjugés sur leur poids de la part des professionnels de la santé.

QUEL SONT LES EFFETS DE LA STIGMATISATION ?

La stigmatisation a un impact sur les politiques de santé, limitant l'accès à une gestion et un soutien de l'obésité fondés sur des données probantes. Pour les personnes obèses, la stigmatisation du poids peut également avoir des effets négatifs sur les amis et la famille, à l'école et sur le marché du travail.



PRÉJUGÉS DE POIDS INTERIORISÉS

En tant que personne obèse, peu importe où vous allez ou qui vous rencontrez, les stéréotypes et les idées préconçues sont toujours là, parfois ouvertement, parfois en toile de fond. Vous commencez à croire que les croyances négatives associées à la maladie de l'obésité sont vraies.

COMMENT RÉAGISSENT LES PERSONNES LORSQU'ELLES SONT STIGMATISÉES ?

La stigmatisation et le préjugé autour du poids interiorisé peuvent entraîner une variété d'effets émotionnels, comportementaux, sociaux et physiologiques. Les troubles de l'alimentation, les pensées et actes suicidaires et l'anxiété peuvent être déclenchés par ces situations.



QUELLES MESURES PEUT-ON PRENDRE ?

Réjoignez notre journée de campagne People First le mercredi 21 octobre 2020. Nous soulignons l'importance du langage des personnes (c.-à-d. « Personne souffrant d'obésité » plutôt que « personne obèse »). Nous voulons être perçus comme n'étant pas définis par notre maladie, mais plutôt comme vivant avec elle. Utilisez notre hashtag #LivingWithObesity pour participer à la discussion !

PREMIÈRE JOURNÉE
DE LA CAMPAGNE
ECPO LE MERCREDI
21 OCTOBRE



#LIVINGWITHOBESITY



ECPO

European Coalition for People living with Obesity

La prise en charge de l'obésité est multidisciplinaire par essence et nécessite un travail d'équipe. De nombreuses personnes qui bénéficieraient de soins médicaux pour l'obésité, n'y ont pas accès.



LivingWithObesity

f/ECPObesity @ecpobesity @ECPObesity in/ecpo-patients www.eurobesity.org

ECPO

European Coalition for People living with Obesity

In den meisten europäischen Ländern erkennt das Gesundheitssystem Adipositas nicht als Krankheit an. Wir können Dich bei der Suche nach Hilfe unterstützen, zusammen mit unserer Gemeinschaft.



LivingWithObesity

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ECPO

European Coalition for People living with Obesity

Az elhízás krónikus betegség, ami kezelést igényel.



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European Coalition
for People living
with Obesity

LIFE STORY

Dealing with Covid-19

BY MAGDA GALIA
ECPO REPRESENTATIVE, POLAND

Magdalena Gąbka - journalist (specializations: health and society), specialist in PR, CSR, social communication and storytelling. The co-founder of 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 story is Magdalena. I come from Poland. I am a person with Obesity disease.

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

October 14 - Wednesday
I wake up at 06.00 am. I have sleep well, but I am weak. For about 1-2 weeks I have been steadily losing my weight. I force myself to wash, drink, 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 train, I feel very faint. With difficulty I come home. My hands shake and I put the key in the lock. My hands on the couch with relief. My head hurts and is pulsing. 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. "But otherwise, not too with respiratory virus, wasn't that plenty of days 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. The sweating, my muscles hurt, so I take medication to lower my fever. I can't fall asleep.

October 15 - Thursday
I wake up before 7.00 a.m. The fever is still high, so I call my family doctor. I ask them for a quick consultation with a doctor. I despair.

be 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 fine 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 reinforced by your insurance is - October 30, but I'll want precise advice then I have to pay for it, and that will take place on - 22 October. The network 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 but in case. Anna is called for me. I live alone. What if something happens to me at night and I don't have the strength to call for help?

Now in 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, paying 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 don't have trouble concentrating. I can 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. She also deals with COVID-19 patients. Katarzyna gives me a private medical consultation - she recommends medications to help me cough and moisturize my throat as well as medications to reduce fever. According to Katarzyna, her opinion is that 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 what 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 overwhelmed 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 read and eat again. But some post COVID-19 symptoms remain. I get tired quickly. I often have headaches. I have attacks of breathlessness that I haven't had before. I am tired of inactivity. But I know home, work and help other sick people.

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

URHealth 4 Life

DEALING WITH COVID-19
Magda Gąbka

COOKING - A MINDFUL EXPERIENCE WITH CHILDREN
Sigrún Thorsteinsdóttir

NEW YEAR, NEW ME TRAP
Barbara Anderson

HOW CAN WE FACE EXTERNALIZED AND INTERNALIZED STIGMA

"As a person living with obesity, no matter where you go, you are confronted by weight bias and weight stigma."

Weight bias is defined as negative attitudes toward and beliefs about others because of their weight. Weight stigma refers to social stereotypes and misconceptions about people with obesity. Weight stigmatization and weight based discrimination occur when we treat individuals unfairly because of their weight and/or size. This is called **externalized weight stigma** (social or structural stigma).

Internalized stigma How does stigma become internalized? As a person living with obesity, no matter where you go, you are confronted by weight bias and weight stigma. You can't avoid believing what the stigma is telling you about yourself, at least to some extent, even when it isn't true. This most often results in self-blame or shame, as well as stress and vulnerability.

Stigma has an impact on the stress level of stigmatized people living with obesity.

Words are important, they profoundly affect the perception we have of ourselves.

Close and trusted friends and family members play an important role in supporting you. If you face stigma from your family or friends, you can also find support in peer-to-peer support groups within patient associations.

Respecting self-esteem is also extremely important.

Forgive yourself, from the bottom of your heart.

Be aware of your positive qualities. List your accomplishments.

Learn to listen to your needs, welcome your desires, respect them, and they will be respected by others.

Create the contact with others.

There are Associations of Patients living with Obesity. These associations offer the opportunity to re-establish social links, to express oneself with others who understand without judgement and to participate in group activities including adapted physical activity, social and playful courses and other forms of social interaction. These activities, in a "protected environment" will help you to get out of social isolation and learn to live again in a society where you may have felt rejected. This is an essential step in regaining well-being, self-affirmation and self-esteem.

EASO ECPO European Coalition for People Living with Obesity

f/ECPOobesity @ecpobesity in/in/ecpo-patients www.ecpomedica.org / www.euroobesity.org

ECPO Magazine

World Obesity Day

Obesity Day Europe

World Obesity Day March 4

COMING UP!

Live Country Reports & NEW Patient video's!

- Germany
- Ireland
- Switzerland
- Portugal
- Spain
- Netherlands
- UK
- Slovakia
- Sweden

SUPPORT WORLD OBESITY DAY EUROPE
#ObesityDayEurope #WorldObesityDay

EASO ECPO

Medtronic

novo nordisk



World Obesity Day March 4

EASO ECPO

Recognition by health systems that obesity is a chronic disease can shift thinking around access to care. Learn, educate and advocate.



WODay.eu #ObesityDayEurope

LIVE EASO ECPO

EUROPEAN OBESITY POLICY CONFERENCE 2021
4 MARCH 2021, ADDRESSING OBESITY: UNLOCKING THE KEY TO RESILIENT HEALTH SYSTEMS

CO-CHAIR

VICKI MOONEY
Executive Director, ECPO

CO-CHAIR

JASON HALFORD
President Elect, EASO

#ObesityPolicy

World Obesity Day March 4

EASO ECPO

Slovenská koalícia ľudí s obezitou a nadmernou hmotnosťou

Prevenencia a manažment obezity sú dôležité po celý život.

WODay.eu #ObesityDayEurope



European Coalition
for **People** living
with **Obesity**

[Home](#) / [Healthcare Hashtags](#) / [#WorldObesityDay](#) / Analytics

The #WorldObesityDay Influencers

Top 10 Influential

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-  [@ECPObesity](#) 100
 -  [@EASOobesity](#) 100
 -  [@ObesityDayEU](#) 92
 -  [@WorldObesityDay](#) 83
 -  [@WorldObesity](#) 78
 -  [@ObesityAction](#) 69
 -  [@ObesityCan](#) 69
 -  [@ObesitySociety](#) 67
 -  [@WHO](#) 65
 -  [@ICPObesity](#) 63

 Tweet

Prolific Tweeters

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-  [@ECPObesity](#) 357
 -  [@ptmariosilva](#) 215
 -  [@solveigsig](#) 203
 -  [@JMBernK](#) 200
 -  [@T2DMBot](#) 123
 -  [@globalhealthbot](#) 118
 -  [@susieb16](#) 112
 -  [@AcSDeV1](#) 102
 -  [@DianeCharleton](#) 97
 -  [@ICPObesity](#) 96

 Tweet

Highest Impressions

-  [@WHO](#) 53.7M
-  [@UN](#) 30.1M
-  [@aajtak](#) 16.4M
-  [@TimesNow](#) 10.2M
-  [@UNICEF](#) 9.1M
-  [@IndianExpress](#) 4.1M
-  [@JagranNews](#) 3.9M
-  [@indiatvnews](#) 3.9M
-  [@UNICEFIndia](#) 3.1M
-  [@UNarabic](#) 2.9M

 Tweet

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

Top 10 Influencers is determined by the [SymplurRank](#) algorithm.

ADVOCACY



How to use your
Real-life Experience to
Influence Change

PATIENT ADVOCACY HANDBOOK

A simple step by step guide
Edition 1: 2021



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)

3 • PATIENT ADVOCACY HANDBOOK



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



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:

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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



