

EUROBESITY

Spring 2021

magazine

WORLD OBESITY DAY

KEN CLARE

THE IMPORTANCE OF THE PATIENT VOICE AT ECO

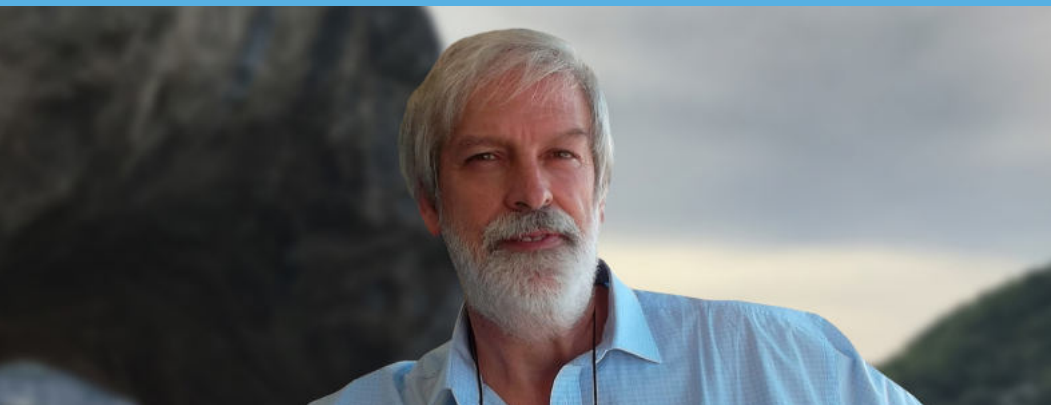
Dominique Durrer

WHAT YOU'RE ALREADY DOING WITHOUT REALISING!

Sophie Millar

EASO
ECPO

WELCOME TO THE DREAM!



Welcome to the new ECPO Newsletter, and to the dream that the whole of Europe will definitely understand that obesity is a biological disease.

Welcome to the dream that in Europe there is a recognized therapy for the effective treatment of this disease.

Welcome to the dream that all people living with obesity are not discriminated against for having obesity.

This dream started in 2006, at a time when the European population was still too shy to talk about obesity. Patients living with obesity hid, they isolated themselves, lived unhappily because they were systematically blamed by society and their families for being overweight, and when they asked for help, their state of health was devalued by those who were supposed to help them: the doctors!

Even so, the dream grew, and, in one corner of Europe, people got together and said:

- **“No!!! We must change this situation!”**

The dream took off and found echoes in other corners of Europe, where other people came together, united by the same will and the same objective and focus, determined to overcome all the difficulties and make this dream come true, declaring with one single voice:

- **“We are here, we are people, we live with a disease and we do not allow ourselves to be treated differently from all other patients with other diseases!”**

Today, there are 25 countries in Europe where committed people have united in this dream with the same common goal.

The journey is long and difficult, but the dream does not die and will be fulfilled.

Carlos Oliveira

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UrHealth 4 life cover photo: by Bjargey



Vicki Mooney
Executive Director, ECPO



Yet again I come to you with one of my favourite phrases... 'Alone we can do so little, together we can do so much'.

2021 began with many hopes, aspirations, and prayers for a better year than 2020.

It has been a turbulent first 4 months of the year with another wave of COVID-19, travel beginning and ceasing, vaccination rollouts and diverse situations across Europe.

However, this has not deterred the ECPO's advocacy efforts, trainings, and public awareness plans. We have created more, shared more, added more bricks to our foundation with prestige and professionalism.

We have been challenged with illness and setbacks and have worked tirelessly and selflessly. Despite this, we have thrived as an organisation, we have supported our national organisations and we have grown as a community. We have celebrated the launch of new patient organisations now in Belgium and Spain, and that is what is important. GROWING the patient community, giving our support to these communities, and giving them a voice on the European stage.

Quickly off the back of WOD2021 (World Obesity Day) with a strong European patient presence, we went straight into organising for ECO2021 (European Congress on Obesity).

We kicked off before the congress

with our own live broadcast of the 'Patient Lounge' and for a change, we interviewed the clinical and scientific community. We teased out their thoughts and reflections on co-creation with patients and the importance of patients having a seat at the table from the very beginning, as we are experts in our own disease.

You can watch this back on our website www.eurobesity.org/pl-od/

I am delighted to report that although this year's congress was held virtually, rather than in person in Malaga (Swoon!). The congress had over 3,000 delegates attend from a vast range of communities.

I am proud to say that the ECPO advocates held their own live sessions on Weight Stigma & People First Language, the patient Voice in Advocacy, their own 'Clinical Roleplay' with Dr Michael Crotty & EASO President Prof. Jason Halford, and co-chaired and represented the patient community in many other live sessions. The feedback thus far has been outstanding and after a long week, I am honoured that we can bring you this Spring Edition of our magazine.

All these achievements would not be possible without so many of us working together. So, I thank this inspiring and resilient team of advocates and I sincerely hope you enjoy reading up on our activities.

EDITORIAL

The importance of the patient voice at ECO

DOMINIQUE DURRER



Researchers, scientists and medical researchers have always focused on their favourite subjects in order to better understand the history, evolution and essence of diseases, as well as their treatment, but without really caring about the patients themselves, their experiences, their wishes or their needs. These two communities have evolved without really communicating.

As far as obesity is concerned, this situation has gradually changed since 2014. Indeed, thanks to EASO and its Director Euan Woodward among others, patients suffering from obesity have entered through the front door and it is important to underline this.

The opinion of patients has finally been taken into account by medical scientists, it is a gamechanger and it advances science.

As a blatant example, thanks to us, stigmatization and its devastating effects on patients have been taken into account and many studies have thrown light on these issues.

Patient-expert, patient-partner, patient-peer, resource, trainer - these are all expressions that refer to the recognition and enhancement of patients' experience.

We at the ECPO, are taking an active role, alongside healthcare professionals, in supporting other patients and training the caregivers of tomorrow. More than just a new profession, the professionalization of these patients reflects important changes in the relationship between caregivers and patients. The generic term "expert patient" actually refers to a multiplicity of roles that these patients can take on, whether in conjunction with other patients, in partnership with health professionals or as trainers in universities for future caregivers.

At a conference such as ECO, "expert" patients can teach what no practitioner has learned in their clinical practice or scientific career, namely, living with chronic disease.

A study by Morgan and Jones (2009) shows that students who attend these courses have a better understanding of the patient's perspective



and develop better communication skills. It is precisely these skills that caregivers may lack, not because of a lack of empathy, but simply because taking the patient's perspective requires learning.

As patients who are experts on our disease, we can give our own insight into the definition of the disease, the links between obesity and psychological difficulties, as well as the person's experience.

For caregivers, hearing the experience of the person suffering from obesity in all its dimensions, including the emotional component, is a key to accompanying them, helping them improve their quality of life and address the issues underlying their weight gain and weight regain. In this collaborative context, patients are legitimized in their position as "health actors", which most often means "actors of their health", but not only.

This is why our presence at ECO remains indispensable. We are privileged to be able to participate in European and International Congresses, to be able to present our needs and experiences and to pass on our own experience of the obesity disease to the participants, as well as to be able to train ourselves to deepen and refine our knowledge in the field of obesity.



Why is it important that members of the ECPO, people living with obesity, participate in the ECO conference?

CHRISTINA FLEETWOOD AND DAVID MATSCHECK



One part of the answer to this question is **stigma**. We have learned a lot about weight bias and stigma in the past few years, about the negative attitudes which are pervasive in society towards people with obesity and the destructive effects these attitudes have on our lives. Stigma is everywhere we go, all through our lives.

Stigma teaches us to feel badly about ourselves. We have always been told that our weight is our own fault, that we lack will-power, and in all kinds of ways are not normal, and maybe stupid as well.

This is internalized stigma, and the self-blame and shame that goes with it. But we can work our way out of internalized stigma, and that way is **empowerment**. Standing up and showing both ourselves and the world around us, that the things stigma is telling us are not true.

Unfortunately, research shows what we know from our personal experiences, that stigma exists among doctors and other health care professionals, just as it does everywhere else in society. Therefore, when we support each other to participate at a conference for researchers and health care professionals, when we make presentations, co-chair sessions, or are just there to listen, we are empowering ourselves and each other.

We are going against the stigma and showing both ourselves and the health care professionals that we are strong, intelligent people, and that we deserve respect.

Another part of the answer is about **knowledge** and sharing **responsibility**.

Doctors have medical training, but we know about living with obesity. Together, we can use our different kinds of knowledge as a shared responsibility. We don't deserve to be blamed for having a disease, but together with health care professionals we share

responsibility, as individual patients for our own care; collectively, to improve care and treatment for obesity; and on the societal level for changing attitudes and making respectful care and treatment available to all who need it.

The personal failure paradigm, the idea that we have high weight only because we eat too much and exercise too little and are too weak-willed to change, is based on stigma and a lack of knowledge and understanding about obesity as a disease. This idea must become a thing of the past.

Instead, we need a model based on respectful and helpful alliances between health care professionals and us as patients.

Participating in ECO, making ourselves seen and heard, is a fantastic opportunity to work against stigma, and for an alliance with health care professionals, and we thank EASO for the opportunity!



World Obesity Day

KEN CLARE



I have been asked to pen a piece about World Obesity Day, and what it means. I was unsure exactly where to start.

Google tells me European Obesity Day started in 2010 and that grew to World Obesity Day in 2015. The history may not be clear but my view from EASO-ECPO in the short time of our existence leaves me in no doubt.

World Obesity Day presents with great opportunities each year. We offer member countries grants to develop activities. We offer a consultancy service to maximise return on investment in activities. These activities may focus around the build up, or just around the day itself.

Increasingly we see activities that leave a legacy for some time after the initial campaign. Our website page at <https://eurobesity.org/home/world-obesity-day-2021/> showcases some of excellent work undertaken. Switzerland, The Czech Republic, Sweden, Slovakia, Italy and Ireland are all featured on that page.

On the eve of World Obesity Day, we held one of our ever popular Patient Lounge events. These have become really popular, with an excellent balance of conversational dialogue and panel discussion.

Vicki Mooney, our regular host interviewed, Steffi, Marion and Andreas from the German patient organi-

sations. They gave a great account of their achievements though joint working.

Maura Murphy (Ireland) Mario Silva (Portugal) joined Audrey Roberts (Scotland) our Vice-President and formed an excellent Panel.

held on World Obesity Day, with Vicki Mooney our Executive Director doing an amazing job of co-chairing the event.

Two of our Directors, Teena Gates and our Chair Ken Clare were also part of the stellar line up.

We had tremendous feedback from the attendees, and this was echoed right across all social media platforms.

On the day, our metrics on twitter, LinkedIn and all the social media exploded.

Its fantastic to feel that we are part of an event across Europe and the world.

This year presented its challenges with restrictions imposed by the Corona Virus Pandemic. I believe we rose to those challenges and exceeded

our expectations.

I would like to thank each and every advocate, organisation and the staff and board of EASO-ECPO for their awesome efforts.

Heres to 2022.



This was followed up by a preview of the EUROPEANS survey data, from Prof. Jason Halford, Shree Bryant and our Chairman Ken Clare.

The European Policy Conference was a tremendous success.

EASO-ECPO co-hosted this event,



World
Obesity
Day **March 4**

Europe

Addressing Obesity Together



WODay.eu

#WODIreland

#ObesityDayEurope

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



WODay.eu

#ObesityDayEurope

ADVOCACY

WHAT YOU'RE ALREADY DOING WITHOUT REALISING!

A SNEAK-PEEK INTO THE ECPO INTERACTIVE PATIENT ADVOCACY PROGRAMME (IPAP) LEARNINGS ABOUT OBESITY

ADVOCACY



Sophie Millar
ECPO IPAP programme facilitator



"Advocacy, policy, public affairs...". Don't let these words put you off – they are not to fear!

When I first arrived in Brussels to start an internship at the European Parliament in 2019, I was completely out of my depth surrounded by colleagues who had studied Politics, International Relations, Public Affairs, EU Policy and so on... And it took me a surprisingly long time to realise that none of this was a barrier. In fact, "policy" and "advocacy" are not something reserved for elite professionals – they are most importantly

something for citizens and patients to engage in. It is key to focus on actions, and not be deterred by words and jargon.

Being an 'advocate' certainly does not require 3 degrees and 10 years of experience!

All it requires is some commitment to a cause, and being equipped with some simple tools to communicate and take action with. It is also important to highlight that being an 'advocate' is not an end-goal, it is a life-long journey, and there is always room to learn and evolve!

I strongly believe that every person is already an advocate without realising it.

To advocate for something simply means to champion for, or speak up about, something you believe in. It is about empowerment and building support. We all want to live in a more equal and welcoming world, and we are all fighting for this in one way or another.

"Advocacy is when a person or organisation publicly supports and champions a cause."

Patient advocacy is about making a change for the people you represent by building relationships with other individuals or organisations.

Breaking down the barrier to advocacy is something which I am passionate about, and I am so honoured to be part of the team working on ECPO's first edition of an Interactive Patient Advocacy Programme (IPAP).

Through this programme, we wish to

bring advocacy and policy to a human level, to make it accessible, and for everyone to feel like this is something they can do and are already doing.

ECPO works to empower patient organisations to build passionate, measurable and sustainable actions that will increase attention towards obesity as a chronic relapsing disease.

This IPAP series draws on best practices and engagement from across Europe to explore how we can engage with policymakers and other stakeholders to shift the dial on obesity policy. The IPAP will bring you through the process of advocacy by simplifying the key steps, from **identifying and prioritising the issues, to implementing an advocacy action plan**. We will be answering questions such as:

How can we better understand our audiences and tailor our messages to engage them and inspire their support?

What actually is a successful advocacy campaign?

How can you stay focused with clear direction?

Each IPAP session, delivered one evening every two weeks throughout May and June 2021, will be conducted in a friendly, relaxed environment, and draw on inspiring examples. Attendees will have a chance to work in small groups to test out advocacy tools for themselves, applying their own experience and skills to reflect collectively on new methods of engagement through a common case study.

Together with the ECPO Advocacy Handbook, this programme will equip advocates and their organisations working on obesity with the tools, resources and skills to develop and implement their own advocacy strategies and better fulfil their policy objectives.

I look forward to meeting some of you online soon!

You can follow Sophie on Twitter @millar_sophie





MY LITTLE
VILLAGE IN SPAIN
María Gomez

LIVING WITH...

NATURE IS MY THERAPY
BJARGEY INGÓLFSDÓTTIR

Dear Reader

Welcome to the summer issue of URHealth 4 Life.
The sun is out, and it is finally summer.

After a hard and stressful winter up here in Iceland, I am so ready for summer with 24 hours of sunlight.

We not only have the Covid 19 scare up here, but earthquakes and eruptions too, and now I have an active volcano so to say, in my backyard lighting up the evenings with lava spoofing up.

This was a big surprise to everyone up here as this area has been asleep for 800 years, then waking us all up in March.

Mother nature is reminding us that we are not in control on this earth.

We have all had our lives turned upside down due to the pandemic, but I am so hoping we are getting there, and soon being able to get our lives back to normal.

We were looking forward to travelling to Spain, to meet up with our friends and colleagues. Hopefully next year if not sooner.

We are bringing a little bit of Spain to this issue, with some recipes and ideas.

Fantastic homemade cooking, who doesn't like that nowadays.
Among other articles from our friends around Europe

*I hope you all have a great summer.
Stay safe and take good care.*



Sólveig Sigurðardóttir
President, ECPO



PAELLA – CHICKEN, CHORIZO AND PRAWN



Recipe by Vicki Mooney

INGREDIENTS

- 4 tbsp olive oil
- 4 skinless chicken breasts, cut into small chunks
- 175g cooking chorizo, cut into small chunks.
- 1 Spanish onion, finely chopped
- 1 red bell pepper, diced
- 3 garlic cloves, minced
- 2 tsp sweet smoked paprika
- 1 pinch of saffron threads
- 2 large tomatoes peeled and chopped
- 300g paella rice
- 1 litre chicken stock
- 200g raw peeled king prawns
- 150 mls dry white wine
- 100g frozen peas

TO GARNISH

- roughly chopped parsley and lemon wedges

PREPARATION

1. Heat 2 tbsp of olive oil in a large frying pan (I like to use a wok rather than a pan or the traditional Paella pan).
2. Cook the chicken over a medium-high heat for 4 minutes. Add the prawns and cook for a further 4 minutes. Add the chorizo and cook for 4 minutes more. Transfer the meat to a bowl.
3. Reduce the heat to a medium setting. Add 2 tbsp of olive oil to the pan and heat gently. Add the onion and red pepper to the pan and sauté over a medium heat for approx. 7/8 minutes until they start to soften.
4. Add the garlic and paprika and sauté for 1 minute more while stirring. Add the tomatoes and saffron threads and continue to stir for a further 2/3 minutes.
5. Add the wine to the pan while stirring for 1 minute then add the rice to the pan continuing to stir as the rice absorbs the wine.
6. Then add the stock, while continuing to stir, and cook for 15 minutes, then stir and add the peas on a medium heat.
7. Do not stir again until the liquid has almost been fully absorbed.
8. Add the prawns, chicken and chorizo. Stir and cook for 4 minutes more.
9. Season, then garnish with chopped parsley and lemon wedges.
10. Most importantly, Enjoy!



BJARGEY INGÓLFSDÓTTIR:

Nature Is My Therapy



I live in Iceland surrounded by incredible nature. I would like to share with you some of my favorite things to do outdoors in Iceland during summertime. I also love to be active outdoors during wintertime in Iceland but Icelandic summer is my all time favorite.

In Iceland we have fresh and crisp air all year round, and when the sun is shining the temperature is perfect for all outdoor activities.



I have loved nature since I was a little girl. I loved being outside with friends, exploring and playing. I was always creating something like building treehouses or playing with whatever I could find, rocks, tree branches and flowers.

I have three children, and as a parent I have always wanted to spend as much time as possible outdoors with my kids.

In summertime we go out for walks in the

woods, we go to the beach, we go hiking in the hills and mountains, and we love to go kayaking in the sea.

We love to make some healthy snacks at home and go out for a picnic.

My kids have a love for animals, and in Iceland we have many farms that are open for families to visit. In some farms you can also pet and feed the animals. We love to go to open farms and sometimes we all go

horseback riding as well.

I love being in water, taking a swim or just floating around and relaxing. In Iceland we have many public swimming pools, nature baths and hot springs that you can bathe in.

Many people swim in the ocean all year around, but I only do that in the summertime because the water is very cold in the winter-time.

In Iceland we have the Blue Lagoon with unique geothermal seawater. The Blue Lagoon is very popular with tourists visiting Iceland and locals love it too. In the Northern part of Iceland, we have Mývatns Nature Baths that contains a large amount of minerals and Sulphur that are considered to have a positive effect on asthma and other respiratory diseases, and many of the trace elements in the water are considered to have a good effect on the development of skin problems.

My family loves to travel around Iceland and see beautiful waterfalls. One of our favorite waterfalls is Seljalandsfoss, and here, you can walk behind it and see the beautiful water fall down from the cliff. The waterfall Gljúfrabúi is also very adventurous to visit, you need to take a short hike into a mountain to see it because the waterfall is hidden inside the mountain.

I use nature to recharge myself. The elements of air and water do some magic for my body and soul.

Being barefoot in water, sand or grass helps me to connect with mother earth, and I can feel the power of energy coming from the earth flowing through my body.

To clear my mind I go out in nature and lay down on the ground to meditate and to see the clouds move above me in the sky. I love to find a quiet place where I can listen to birds sing or be near natural water streams or waterfalls and listen to the relaxing sound of water running by.

If you would like to see some photos and videos from Icelandic nature you can follow me on INSTAGRAM - ***bjargeyogco***

I hope you can find some beautiful places to visit this summer, enjoy being outdoors and let nature be your therapist.

Bjargey Ingólfsdóttir
ECPO Patient Council Representative
from Iceland





Living with... Cancer

Marion Bagnall



My journey with obesity began back in 1992. For the first 34 years of my life, I was your average weight give or take a stone (6kgs).

That all changed with a head on traffic collision, which left me out of work for 2 years and with some serious injuries.

In the first few months after the accident, I gained two and half stone, and over the next 4 years I went from ten and half stone to fourteen and half stone.

During that time, I changed jobs as I could no longer work at my old job because of the injuries I had sustained.

I went for an interview where my weight was subtly mentioned. This was my initiation into the world of prejudice.

Over the next number of years my weight fluctuated up a stone or two, or down a stone or two.

I had five pregnancies over six years, and while pregnant, I never really gained much weight. But sadly, I lost three of those babies and I comfort ate as I was very depressed.

By 2002 I weighed eighteen stone, and had begun to be very self-conscious even though to others, I appeared otherwise.

I have to say I did not get very much hassle from any of the general public whether it is the way I carry myself, or that I have been lucky with the people I have met in my life.

I have met some truly genuinely nice healthcare professionals. It is like in any walk of life, they are a mixed bunch.

Sadly, not all the medical professionals are nice, and some can be quite rude and insensitive, and that is me being generous.

No matter what medical complaint that I have had, my weight was frequently mentioned.

I have Type 2 Diabetes, and I had the most amazing consultant who never judged me on my weight and who was encouraging and supportive.

I cannot say the same of his successor, unfortunately he is obsessed with the numbers on the scales no matter how good your HbA1c is.

In December 2019 I was diagnosed with Breast Cancer, and my treatment at St James's Hospital in Dublin began, and I am still here thanks to their fabulous team...

But my Cancer would not have progressed as far had my GP listened to me.

In early March I had gone to him feeling very lethargic, I could not function well. His first response was that I was tired because of my weight. My answer to this was that I have a very active life, and why after

over twenty years of carry this weight, should I suddenly be so tired?

I listed off my day for him 06.30 to 22.30. We have our own business, I cared for mum (R.I.P.), my husband, our two children and I also have three dogs that got walked twice a day.

Additionally, I was also involved with a lot of voluntary work. But even so, my GP thought he knew best, and sadly it nearly cost me my life.

By the time my tumour was found in November, the cancer had already spread to my Lymph Nodes.

Had I been sent for a scan in the March, a whole seven months sooner, I would not have had to have the two surgeries, eight rounds of chemo, and twenty intensive radiotherapy sessions.

When I met with the surgeon and he gave me my results, my first question to him was "Is this because of my weight" his answer to me was "no not all, you are a woman, you have a one in four chance of getting breast cancer".

To this day, he has been an absolute gentleman and never once has he mentioned my weight.

I was correct about my fatigue, my cancer was hormone based and hence, resulting in the tiredness and lack of energy.

My lesson from this, is not to be afraid to challenge the professionals in your life that think they know your body better than you.

If my story helps just one person to find their voice, I will be so glad I shared my experience.

Living with...



I have known about my eye condition "Myopic choroidal neovascular membrane - non age related" since I was approximately 10 years old, but the symptoms didn't manifest themselves fully until around 2009.

My eye condition doesn't make me who I am, and it certainly does not define me, which is exactly the same for my obesity. What does define me is my character, as well as my positive attitude towards life!

- Audrey Roberts

Living with...

Living with... NASH

Hana Vrabcová



My name is Hana, I live in Bratislava, the capital of the Slovak Republic. When I think of my childhood, I suffered from obesity. I did not like physical education, it always ruined my school report, and I was unhappy about it. I did not realize the stigma then.

By changing my lifestyle and environment, by studying at the university in Bratislava, I managed to reduce my weight and my BMI was fine (waist size was 68 cm).

I wanted to lose weight after giving birth, but my jealous husband did not allow it, I gave up as I do not like conflicts.

Later, I started putting on weight again, I had a Grade 1 obesity and high blood pressure, a metabolic syndrome started along with an enlarged waist size.

About 5 years ago I was diagnosed with high cholesterol and started taking medication for this disease. Last year, during an examination on a FibroScan Device, within a research work of Doc. Belovičová, I was diagnosed as Non Alcoholic Steato-Hepatitis (NASH) in an initial stage, due to long-term overweight.

I was incredibly surprised because my liver tests were fine. The doctor explained to me that NASH is an inflammation of the liver and arises as a result of fat storage in the liver. In patients living with obesity, lipogenesis (fat synthesis) in the liver is most often caused by excessive consumption of high-sugar foods.

When we take in more calories without compensating for physical activity, fat damages tissue, scars form on the liver, fibrosis and

later cirrhosis occurs, and liver failure occurs.

I try to control my appetite and keep my weight low. I know how to change my eating habits, limit sweets and farinaceous meals, and to eat lots of vegetables.

Also, to exercise so that my muscles produce myokines, hormones of muscle tissue that have an anti-inflammatory effect and effectively affect our organs.

Due to the Covid 19 pandemic, things have been hard now, for well over a year, and because of my passion for work and its resulting stress, I sometimes forget to eat and drink, and the body remembers that.

Obesity is not considered a disease in our country, where only its consequences are treated.

This fact alone has a significant economic impact on increased costs in healthcare and other sectors of the state.

Many people do not even know how many, and what diseases arise from obesity, including the effects of Covid-19, and what the consequences may be for their health.

According to experts, more than 60% of people in Slovakia are overweight or have obesity.

Many of them do not know just how dangerous obesity is, they think, "I'll take a pill to lower a pressure, to treat heart pain

or to lower sugar levels, and I'll be fine." They have no information that obesity can be prevented by diet, exercise, and a change in their habits. I am delighted that as a member of the ECPO EASO Council, I am receiving information on how to tackle obesity and its prevention, with cooperation and support in our activities from colleagues from all over Europe.

Proof of this, is a publication of a special edition of the book "Treatment of obesity for primary care physicians and internists" by Dominique Durrer and Yves Schutz in Slovak translation. This publication is published with kind consent of the authors to WOD Europe 2021 and is the first publication of this kind in Slovakia.

In my opinion, there is a need for European wide recognition of obesity as a chronic disease, there must be an effective system of prevention from the very beginning of life, and a system of paid healthcare in obesity.

Equally important is to ensure that all people are educated not only about obesity but also about diet and its composition, and its role in people's lives, eating behavior and the importance of exercise, and make commitments among countries to comply with recommended measures on prevention and treatment of obesity while at the same time, to adopt the Obesity Charter.

RNDr. JUDr. Hana Vrabcová,
President of the Slovak Coalition of People with Overweight and Obese (SKLON) www.sklon.sk



Living with...

Living with... Bipolar

Ken Clare



My names Ken, I am from Liverpool in the UK. I am 60 years old and I have lived with obesity all my life.

I have lived with other diseases too. Just for now, I am going to talk my bipolar.

It is a mental health problem and I have lived with scary out of control highs and at the bottom of severe depressions, and everywhere in between.

I have not always been sure when things were changing. I guess I always knew my moods were "changeable." It was only after a couple of depressive illnesses and a period of being high did I get a diagnosis.

The diagnosis is a bit of a mixed blessing, it came with a stigma and problems, but it enabled me to get better access to the healthcare that I needed.

I have had a great family doctor, a supportive family and a succession of mental health professionals in my life, and I have a few friends I can talk to about these things.

I also have the advantage of being a mental health nurse.

Though getting ill in a city where you used to manage the mental health services wasn't easy.

I have to do things every day to keep myself well. Most of them are tedious.

I must take a "cocktail" (the word that psychiatrists use) of medication to keep me well. Two mood stabilisers, an antidepressant, and a titrated dose of a "designer" antipsychotic.

The drugs make me feel dreadful in lots of ways.

Lithium has been described to me as a "dirty drug", with a fine line between it not being effective and keeping you well, to poi-

soning your liver, kidneys and other offal. It can also cause a toxic confusional state too.

I once spent some time in our local general hospital completely confused, for several days, not an experience I want to repeat.

I reluctantly take it each night, and I need to remember that it is probably keeping me stable.

I have blood tests regularly to check the levels in my blood. Not too low, but therapeutic and not toxic.

I have a little card in my wallet that I am supposed to show new doctors, but I forget. Its in my medical history on my phone if anyone checks.

Each of the drugs for my mental health cause weight gain. That is a frustration, when already my starting point has been living with obesity.

Sleep is vital for me. If I don't have enough sleep, I can be triggered into a full blown high. I take sleeping pills, but the medical team supporting me

decided a while back, the harm from them is outweighed by the risk of a hypomanic phase. New doctors like to counsel me about taking them.

I am hung over every morning. I struggle for the first hour or so and I go to bed early. When we were travelling, pre pandemic, you would often see my wife or a trusted friend with me making sure I do what I need to do, to keep on an even keel.

I decided early on, alcohol and non-prescribed drugs make things a whole lot worse, so avoiding them makes things easy.

When I was first diagnosed with my bipolar, I refused to comply. It is an illness that tells you that you don't have it, although I was also in denial, I didn't want to believe.

For a month I spat my tablets in the toilet, and my rapid admission to hospitalisation convinced me compliance was the best

course of action.

I attended the local bipolar support group, and just listened. They wanted volunteers, but my family doctor wisely advised against volunteering.

I was once on a committee looking at self-management and early intervention for bipolar.

I learnt what my warning signs are for going high, or going into depression are. I know what to do, as does my wife.

The NHS in the UK struggles to deliver everything needed. I understand that, and I always try to be patient. So far I have been blessed.

Just recently I had been overworking, without rest, with no let up, and my mood was rising, and after medicating to stave off a high, I was slipping deeply and quickly into a severe bout of depression.

I contacted my GP by email and got an urgent referral to my mental health team.

The psychiatrist called me three weeks later. Luckily I was ok, I had done the right things and stabilised.

The psychiatrist reminded me that we have a crisis team, but they are stretched to the limit, that they have to focus their resources.

So I accept that I live with bipolar (I am not even sure that is the right term to use). I avoid controversy about it.

It is what it is today. I just try to do the next right thing to stay well.

Ken Currently is the Chair of the Board of Directors of EASO-ECPO The European Coalition for People Living with Obesity. (ECPO)

Director of Bariatric and Metabolic Surgery Services Obesity UK.

Board Member of The Association for the Study of Obesity (ASO)

Visiting Fellow in Patient and Public involvement at Leeds Beckett University.



Living with...

Living with... Lipoedema

Elly Juerissen



My name is Elly. I live with obesity and Lipoedema.

I am a statistician and a scientist by heart, and I have been living with obesity for many years now.

I was not fat as a child, but I did gain some weight when I was about 18 years old, which turned out to be common for some women in my father's family. Thus, I started to diet for weight loss, at first only 3 kgs, but I gained more weight than I lost with each weight loss attempt. Therefore, about 30 years ago, I decided not to undertake anymore diets, for weight loss.

As I had lost my sense of boundaries for what healthy food was, I used the help of a professional dietician. The resulting change to healthy food and more movement did lead to weight loss, but because of my history of disturbed eating, I did need to be careful not to develop an eating disorder again, and the dietician worked with that. Part of that is psychological, so we focused on health, not on weight loss. Weight loss can be a goal, and in this case has been a result, but it was never the focus goal. Health was, and still is.

One frustration I have is that, while the 'goal' for weight-loss is 5-10%, and while I have lost more than that, almost every new health care professional I meet wants me to lose weight, and even though I try, it is very hard for me to get them to discuss the science with me.

I am also living with Lipoedema. Lipoedema is not a rare disease but it is not well known and often diagnosed and treated as obesity. The most obvious difference is that with Lipoedema touching the affected fat is painful.

Another way is to check for this, the clothing sizes for your upper and lower body. If you would need a much larger size for your lower body than your upper body, you could very well have Lipoedema. For instance, lar-

ge thighs and hips but smaller shoulders, and not much fat on feet. It is possible to have Lipoedema in the arms or in the belly, but those are rarer than Lipoedema in the legs.

In my case I did get a diagnosis of Lipoedema in the early 2000, but not a clear one, and not a clear treatment, the only treatment was compression stockings up to the knee, which they then did not make in a way that I could keep them on. So, I lived with untreated Lipoedema for many years. As a result, I developed lymphedema in my right leg, diagnosed in summer 2020.

I moved, and was now under the care of a professor specializing in both Lymphedema and Lipoedema, and because I now had Lymphedema, I was eligible for a 3-week outpatient hospital program, including daily compression bandaging, daily exercise, and an education program on Lymphedema and Lipoedema, a visit with a psychologist, and dietician in addition to the prescription of compression stockings, for both my legs, and this time high stockings.

I am happy to say that this worked. Both my legs now thinner. I have much less pain and moving is easier, and because of the exercise, my legs are much stronger, and I definitely have more energy. Sadly though, the corona virus pandemic closed my fitness centre, so I now do some exercises at home.

Gaining weight worsens the Lipoedema, Obesity treatment, is a no-no, and losing weight does not decrease the fat deposits of the Lipoedema. As in my case some of the Lipoedema fat deposits are on my lower leg, and I have some discolorations on my shins, I do not wear skirts. But with the compression stockings that might change, the discolorations are hidden and the fat deposits are

compressed by the stockings.

I would like to see awareness of Lipoedema become more known, so that other women with this disease might get treatment before they get complications, and before they get into the higher stages of the disease. I can truly say that wearing the compression stockings is much better than not wearing them, even if they are a class III, which is a fairly high class. They are expensive, especially because they only last 6 months. Luckily, again because of the complication of Lymphedema, I get most of the cost reimbursed by our Belgian health insurance.

But I would very much like to see that people with only Lipoedema, also get their compression stockings reimbursed, because they need them too! I don't yet know how this will be in a hot summer, because I got my first pair in September.

<https://commons.m.wikimedia.org/wiki/File:Lip%C3%B6dem.jpg>

Photo from Wikimedia.org, which shows a photo of a woman living with severe lipoedema in the (right) leg, as the kneecap is covered by a hanging lipoedema. She is also living with obesity, as shown with the hanging belly covered with a knit higher in the picture. I don't have the hanging lipoedema, but otherwise my leg is similar to this lady's leg.

I am a patient representative with the European Coalition for People Living with Obesity for Belgium and I have just recently become a founding member of Pacte Adiposité – Adipositas Pact and our aim is to be the authoritative patient voice in Belgium with respect to evidence-based approaches for obesity prevention, treatment, ongoing management through policy change, by facilitating knowledge exchange, patient-led research and advocacy.



Living with...

My little village in Spain

MARÍA GÓMEZ



My name is María Gomez. I am from Iceland, and I am the face behind the lifestyle blog www.paz.is. I love making beautiful things around me and cooking good food. Paz is derived from my grandmother from Spain. Grandma Paz was an artistic chef.

She was, and is one of my role models in life, so I thought it would be great to name my blog after her.

Paz translates to peace in Spanish.

I am married, a mother of four children, and I have a degree in tourism from the University of Iceland.

I am very interested in photography and take most of my photos myself.

As my name suggests, I'm half Spanish, and Spanish culture is therefore a big part of my life, and Paz is therefore slightly under Spanish influence.

Lugros, my little village in Spain, is a lovely 400-person village, with whitewashed houses, at the top of the Sierra Nevada National Park.

The national park is located in the province of Granada in southern Spain.

The name Lugros means wolf, previously there were a lot of wolves in the mountains, which today are sadly extinct.

The mountains also contain the Spa-



nish mountain goat, which is in danger of extinction, and there are fines or imprisoned for killing or damaging one.

One of the things I enjoy most when I come to Spain, to visit my people, is sitting at a Spanish table. It is as different from Icelandic dining as possible.

Being in Lugros is like an adventure. The inhabitants there are very short, and I think the medium-sized woman from elsewhere is very tall in their eyes. I regularly hear "que

alta" which means "but tall", which I always find very funny as I am 164 cm tall.

The village is made up of several clans and my clan is one of them. I have no idea how many people living there are related to me.

I remember when I went there at the age of 13, right after loading, I got a complete culture shock, and almost needed trauma care.

There I had to kiss everyone on both cheeks and every other person was my cousin.

I had not been to the village since I was a toddler and did not remember much about it, but I was raised in Gerona, Catalonia until I was 5 years old.

I'm very glad to have been able to go there, because since then I always go up to the village when I travel to Spain.

I stay with my paternal aunt Tita Paz, (Aunt Paz), who is always in a good spirit as we have spent countless hours in the kitchen together cooking tasty Spanish food.

I will give you some recipes for the Spanish food and there is more to find on my blog.

My family owns a lot of land in Lugros. There you will find figs, almond and olive trees and last but not least vineyards and much more.

The Spaniards think a lot about food, and food plays a very big role in their minds. They start wondering what to have for dinner the





day before, and more often than not, they start cooking early in the morning.

Often when I talk to my paternal sisters across the ocean, the question of what I had for dinner is the first after *Cómo estás?* Or how are you?

The Spaniards are very attached to their culture, and it is still common to take the so-called Siesta.

Siesta is between 14.00pm and 17.00pm, but then many shops and offices close and employees go home to eat or to the beach.

Two o'clock in the afternoon is usually the family's main meal, but it's also the hottest time. Siesta was originally created due to the heat at that time, but before that, it was almost unbearable to stand in a store or sit in an office at this time of day.

Nowadays, this has only slightly changed, especially in the big cities of Spain, where shops are often open all day. Most people take siesta, although now there is a good ventilation and air conditioning systems in most of Spain's stores.

Siesta means nap in the direct sense, though the word signifies a little more than just that. It really means that time between 14.00pm and 17.00pm when everyone goes home to eat and go to bed.

Children and adults often take a nap at this time, but in the summer the younger generation often go to the beach instead if it's nearby.

People also often lie in front of the TV and watch one particular South American soap opera that is often shown at this time. There is a lot of betrayal and drama that is often played with a lot of gestures and hand movements.

Housewives in Spain set the table for the family and cook a variety of dishes.

It is often customary to have a main course, salad and bread, and then maybe something else that is used from the day before.

Everything is used and nothing is wasted. Then the family sits at the table more fully and enjoys the food and chats about what has driven the day. There is often a salad

prepared on a large plate that is placed in the middle of the table.

Then someone at the table is given the task of sprinkling oil and vinegar and salt over it.

During the meal, everyone eats with their fork from the salad that is in the middle of the table, but not everyone gets their own plate, this creates a certain atmosphere at the table and connects people.

When the main meal is over, you may sit down and have fruit or yoghurt to complete the meal. Cheeses and cold cuts such as raw





ham are often pulled out and continued to be eaten.

Spanish raw ham, bread and cucumbers with oil and salt are very popular in Spain as a dessert, side dish or starter

Typical Spanish desserts



This is called a “postre” or dessert and it does not always necessarily mean cake, ice cream or something sweet.

When everyone has had something to eat, they continue to sit at the table and then pour coffee.

The coffee is sometimes served with something sweet, such as Torta’s Spanish pastry (bread with sugar on top) or even something else.

It is not uncommon for something sweet to be eaten with the coffee, but coffee is still always on offer.

During this long meal, the whole family sits together and chats, both the children and adults, and I always remember from when I was a child, this a special and wonderful time spent with the family.

Eating in Spain can often go well for up to 1 and a half hours, even longer. where everyone sits and eats together in peace.

Often the Spaniards eat nothing from noon until the evening, except perhaps a cup of coffee and something small. Kids, on the other hand, often enjoy a bocadillo sandwich and Cola Cao, which is the most well-established cocoa brand in Spain.

Bocadillo is a sandwich made from a baguette or ciabatta and usually has toppings such as raw ham, chorizo, omelette and grilled peppers or tuna.

Kids in Spain all too often get to nibble on “pipes” between meals. Pipas is a sunflower seed that has a skin and has been salted well.

The pipe is inserted whole into the mouth, with the skin and everything, and then it is a good idea to bite the skin apart between the jaws and remove the sunflower seeds with the tongue and then spit the skin out of the mouth.

I have often tried to give this to my Icelandic friends in Spain and enjoyed seeing them try the technique of eating pipas.

They also sometimes get churros con chocolate or even some other sweetness like a sugary Spanish donut called rosco.

In the evenings, dinner is often eaten very late, often not until 20.00pm or 21.00pm and often even later.

The shops and offices close, and people go home after the day.

In many homes, the table is already set for dinner and lunch, and you sit at the table for a long time and eat well, varied and rich food.

Since I am from Andalusia, I have the appreciation of that food culture, and my favorite Andalusian dishes are Fritada de Pollo, Pollo al ajillo, Arroz con gambas, Potaje, Arroz con leche and Churros con Chocolate to name a few.

You should be able to order these dishes at most real Spanish restaurants.

SPANISH CHURROS CON CHOCOLATE

RAW MATERIAL

250 ml of water
55 g unsalted butter
1 tablespoon sugar
1/4 teaspoon salt
140 g flour
1 large egg
1/2 teaspoon vanilla extract or
vanilla drops
1 litre of vegetable oil

Sugar to roll from:

1/2 cup sugar
3/4 tablespoon cinnamon
The chocolate with the Churros:

100 gr 70% chocolate
1 dl cream
pinch of salt

METHOD

Churro

Start by mixing the sugar and cinnamon together on a plate.

Now let's start with the churros itself
Put water, butter and sugar together in a saucepan and start to boil, then lower the heat to medium heat.

Add the flour to the pot little by little and stir well in the meantime, much like when you make water dough buns

Now transfer the dough to a bowl and let it cool for about 5-10 minutes with an open window

Then add vanilla and egg to the bowl and immediately start beating with a hand mixer, until the dough is silky soft and well compressed into a ball.

Put the dough in a syringe bag with a rather large star nozzle

I like to spray dough on greaseproof paper into strips and cut around each strip, so everyone gets their cardboard
Now heat the oil in a deep pan and put some dough on top to see if it is hot. When it's hot, lower the particle below it, not much just a little

Now put like 3-4 strips of greaseproof paper on the oil and remove the cardboard with tongs immediately, very convenient to do it like this so that no oil splashes on a person

You can go to my Instagram and see how I do this under highlights

Fry until they are golden brown, and make sure to keep them long enough, so they do not become raw inside.

Then place on top of a plate with kitchen roll to absorb all the extra oil

Finally, they are rolled out onto the sugar mixture

The chocolate

Put everything together in a saucepan and stir constantly while the chocolate is melting
Then serve hot with the churros

It is quite clear that kids as well as adults love Churros in this household, so I definitely recommend you give it a try.

Good luck to you



ARROZ CON POLLO

Serves: 4-6

RAW MATERIAL

1 tray of deboned chicken thighs or c.a 700-800 gr
 1 green pepper
 1-2 red peppers
 1 onion
 1 garlic
 1 cup of green beans (I use frozen)
 1-2 chicken cubes
 1 fish cube
 1-2 large tomatoes or 5-7 small plum tomatoes (you can skip and use 1/2 can of chopped tomatoes or 1 tablespoon tomato puree)
 1 and a half glasses of porridge rice or Arborio rice (very important that these rices are used).
 5 glasses of water (use only the usual size of glass but make sure to use the same glass for the rice and the water for the right ratio)

Yellow colour called colorant or Turmeric. It's nice to take a colorant home with you from your summer holiday in Spain, but it is available in all supermarkets in Spain) you can skip it completely, it's just used to get the yellow colour on the dish.

Salt and pepper

1/2 dl Olive oil

For those who want, it is really good to add scallops, mussels and shrimp or lobster to this dish, but I also often buy one package of seafood mixture to add and it is very good.



METHOD

Cut the onion into small pieces and mash the garlic. Cut the peppers into long thick strips and the tomatoes into small pieces.

Cut the thighs in half

Heat olive oil in a large pan and add onion, tomato and garlic and lightly salt and pepper.

When the onion is soft, put the peppers on top and lightly salt again and allow them to soften even at a low temperature.

Be careful not to burn the onion.

Next, place the chicken all over the pan and stir in everything and salt and pepper again. At this stage, the seafood dishes are also placed on the pan if you enjoy the ones I recommend.

When the chicken is just starting to turn white, place the greens all over and stir well so that they go in between everywhere.

Next, the water is boiled in a kettle and the cubes are dissolved in it.

Then pour it all over and stir for the last time.

Be careful not to stir the dish anymore while it is boiling.

Now pour green beans over everything and the colorant colour and cook for a further 25 minutes on a low heat.

When the dish is ready, the rice should be soft, and a little extra broth should be on it.

Do not worry that the water is not all evaporated because it should be like this.

POINTS

I recommend serving the dish with freshly baked sliced bread to dip into the dish, but I usually buy frozen from la baguette which I heat in the oven while I make the dish. It is also good to serve garlic bread with this dish.



In the frontline

BY STEFANIE WIRTZ



My name is Stefanie Wirtz, I am 43 years old, and born in Essen. I grew up with my parents and 2 younger siblings in a village in Münsterland. I have been suffering from obesity since I was 12 years old.

Even in my childhood I didn't always have it easy and was often teased and bullied by classmates. I have never let myself be told that this is offended by me. I built a protective wall, which usually led to secret food at home.

At school, especially in sports, I was always laughed at. In group sports I was never voluntarily selected for a group, which always had to be decided by the teacher which group I was allowed to participate in.

After my pregnancy and growing up, my now grown-up daughter, I realized that I can no longer do justice to my child. I didn't have much mobility (climbing, running, playing on the floor), so I decided to seek medical help. At that time, unfortunately, there were only a few qualified doctors in Germany who took up the subject. So I had to do a lot of research on the Internet alone.

In 2009, after a long period of preparation, I had all the documents and examinations together to get a gastric bypass. I needed 6 months of nutritional therapy, a psychological assessment, blood tests and a surgical assessment.

Since then, I have also been working for those suffering from obesity.

In 2009 I founded the 1st self-help group in my region. It was important to me that people with obesity have a point of contact, who could exchange ideas with like-minded people and support each other.

At that time, I worked as a service manager at Deutsche Bahn.

In 2017 I quit my job after 23 years, and only wanted to pursue my hobby full-time, to help and support people.

After several training sessions, I started a new job in 2017 in a hospital as a specialist coordinator for obesity and metabolic surgery. In this context, accompany and care for people with obesity on their way. This job is always exciting. I am happy to see the development of those affected and to support them no matter what therapy option they choose.

Since March 2019, and the beginning of the Corona Virus Pandemic, unfortunately everything has become more difficult for those affected.

During the 1st lockdown in Germany, non-essential surgeries had to be cancelled, nutritional therapies could no longer take place. Sports and the meetings of the self-help groups were forbidden. No group sport has been held for 1 year.

But it is precisely this group sport that has always been very supportive of those affected in doing sports at all. In a group, they are not alone and feel safer than if they had to go to

a gym alone. The self-help groups now meet online and nutrition therapy has also found its way into the digital world.

For the future, I hope that there will be a single and funded treatment for obesity for all people. Everyone should have access to the therapies they need without having to jump big hurdles. I would also like to see acceptance in society.

Stigma is a very sad issue, especially when you see how the individual affected suffers. I hope that people who suffer with obesity will no longer be seen as lazy and greedy, but as who we are. People with a chronic illness.

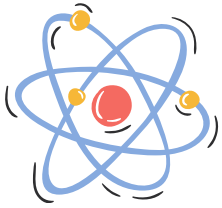
At the moment I work both at home in the home office, and give advice over the phone.

But I also work on site in the hospital 2-3 days a week. Consultations take place there, as well as the important follow-up examinations and discussions for those affected who have had a bariatric / metabolic operation.

When the Corona Virus became known, I was very worried. Now I'm hoping for quick vaccinations so that maybe more normality can take place again in the near future.



REMEMBER



Obesity is a chronic relapsing and complex disease.

People **DO NOT** fail treatments, treatment **CAN** fail people.

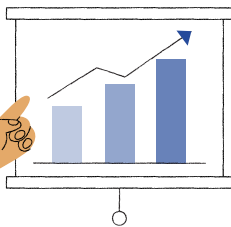


Overeating does not cause obesity, **obesity causes overeating.**

WORDS Matter! We are 'People First', People before our disease.



Obesity is not a lifestyle disease.



Obesity is up to 70% Genetic.

The true goal is healing and health.





EurObesity Magazine Team

Chief Editors: Vicki Mooney, Sólveig Sigurðardóttir, Susie Birney

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