

22  
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2024

2nd INTERNATIONAL SYMPOSIUM  
**POST COVID SYNDROME  
AND CHRONIC FATIGUE  
SYNDROME**

METHODOLOGICAL ASPECT  
OF DIAGNOSTIC AND TREATMENT

EDUCATIONAL SYMPOSIUM OF THE EUROPEAN BOARD OF CLINICIANS,  
RESEARCHERS AND PATIENT ASSOCIATIONS FOR CHRONIC FATIGUE  
SYNDROME

EMERO / EMECC / EMEA

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Accreditation by Health Council Serbia



Gracemarie Bricalli  
President of the European ME Alliance  
[www.europeanmealliance.org](http://www.europeanmealliance.org)



# European ME Alliance (EMEA)

- Founded in 2008.
- Voice of people with myalgic encephalomyelitis (ME or ME/CFS).
- Advocate for biomedical research and better outcomes for patients.
- Composed of 18 member countries and growing:  
Belgium, Croatia, Denmark, Finland, France, Germany, Iceland, Ireland, Italy, Lithuania, Netherlands, Norway, Serbia, Slovenia, Spain, Sweden, Switzerland, UK

Myalgic encephalomyelitis (ME or ME/CFS)  
occurs more often than you may be aware of.

It can affect anyone at any time.

# ME/CFS – Prevalence

The [European Parliament's 2020 EU Resolution on ME/CFS](#) reports there are about 2 million people afflicted in Europe and 24 million diagnosed globally – numbers which they estimate to be 10% of those affected = **240 million people worldwide.**

## Resolution Text

*“whereas according to the Commission’s answer of 30 August 2019 to Petition No 0204/2019, ME/CFS is diagnosed for around 24 million people worldwide but this is considered to be only 10 % of the total ME/CFS population.”*

*“whereas approximately two million people in the EU, of whatever ethnicity, age or gender, are believed to be afflicted with ME/CFS; whereas among adults, women are the most affected;”*

# Worst Quality of Life

A 2015 [health impact study](#) by the Danish ME Patient Association, reported that people with ME/CFS experience **'the worst quality of life'** of all the diseases surveyed, surpassing even the dreadful effects of chronic obstructive pulmonary disease, lung cancer or stroke.

# Defining Symptom: Post-Exertional Malaise (PEM)

**Many healthcare professionals are not aware** that Post-Exertional Malaise (PEM) is the defining symptom for ME/CFS.

People are severely physically ill, despite their symptoms being self-reported and seemingly 'invisible'.

**NICE Guidelines on ME/CFS** define PEM as:

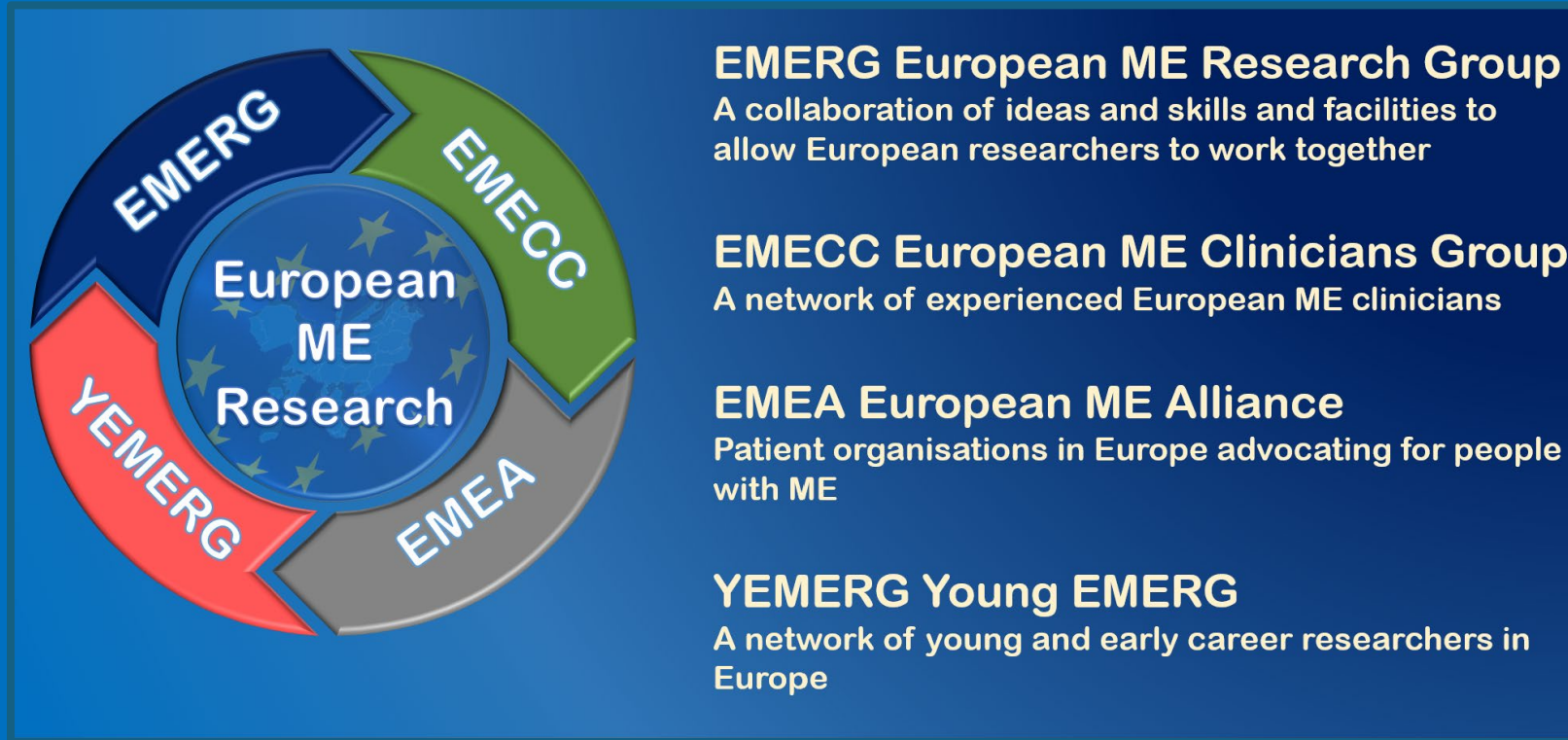
- *The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity.*
- *Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks.*

People may not look sick, but they are unable to perform their normal activities.

**PEM makes people's ability to function, go to school, or work, unpredictable.**

# European framework for research

Due to neglect by governments, it has been left to EMEA and its members to initiate, coordinate, and fund research in Europe, including an annual conference, with our limited resources.



- <https://emerg.eu/euomeresearch.shtml>
- <https://www.emerg.eu/em-team.shtml>
- <https://www.investinme.org/index.shtml>

# Strategic partnerships



**WHO Europe:** EMEA is an officially accredited Non-State Actor and collaborator, working with WHO to leave no ME/CFS sufferer behind.

## **European Federation of Neurological Associations**

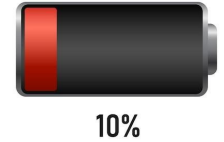
**(EFNA):** EMEA is a member of the Board of EFNA, because **ME/CFS has been classified by the World Health Organization as a neurological condition since 1969** under ICD-10 G93.3 and more recently ICD-11 8E49.

**European Disability Forum (EDF):** EMEA is a member of EDF because we endorse the UN Convention on the Rights of Persons with Disabilities, because ME/CFS is a severe, long-term, complex, chronic, systemic disease, that causes severe disability even in its mildest form.





# A day in the life of an ME/CFS sufferer



1. You wake up just as tired as you went to sleep.
2. Your room is dark with the curtains drawn because you are sensitive to light and sound.
3. Your energy level is 10% and you need to decide what you can do – eat, or brush your teeth, or get dressed – because you barely have enough energy to do one of them.
4. If you try to do more, then typically 12 to 48 hours later, you experience for example, brain fog, the inability to process information, to read or write, watch TV or listen to music.
5. That means for the coming weeks there is only the ceiling to look at, since you do not have the energy to get out of bed or do anything.
6. Hopefully, you have family or friends who believe you and take care of you (e.g. cook for you, feed you, pay your bills, do the laundry, go shopping), and organize medical appointments at home because hospitals lack dedicated rooms that protect ME/CFS patients' sensitivities.
7. You feel vulnerable, traumatized, isolated, and defenseless.
8. **REPEAT.** (Sadly some people lose hope and **resort to suicide**)

EMEA survey of  
ME/CFS patients in Europe

Same disease,  
different approaches  
and experiences

By Arild Angelsen and Trude Schei



## The EMEA Survey of ME/CFS Patients in Europe

To gather data on the patient experience EMEA conducted a [survey](#) that shows that over **11,000 patients**, from 41 European countries and 3 non-European countries, reported that **ME/CFS sufferers desperately need assistance NOW**.

The survey results were published on World Health Day 2024, under the slogan **'My health, my right'**.

Summary information is available in several languages on the EMEA website.

# Serbia: Profile of survey respondents

- There were **142 survey respondents** from Serbia.
  - **61% had received a diagnosis.**
  - 9% were currently under evaluation for a diagnosis.
  - 29% believe they have ME/CFS, but are neither under evaluation nor had received a diagnosis.
- The **average age** of respondents was **42.9 years of age.**
- **78% of respondents were female**, 22% male.
- **Average time from disease onset to diagnosis was 6.7 years** (7.4 years for men and 6.6 years for women).

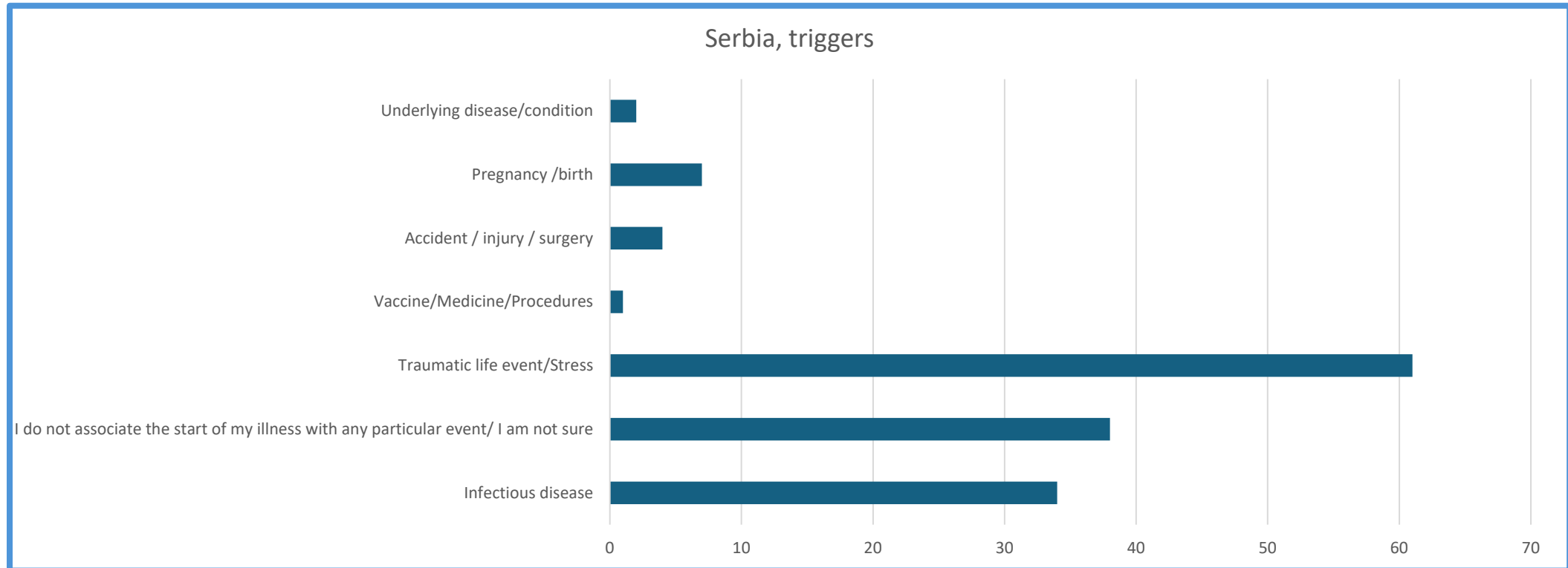
# Serbia: Severity of ME/CFS

The survey used the severity scale of the **International Consensus Criteria**.

- **15%** of respondents said their disease was better than mild = **less than 50% loss of function**.
- **27%** had “mild” ME/CFS, which means **at least a 50% loss of function**.
- **45%** had “moderate” ME/CFS, which means that the patient is mostly **housebound**.
- **12%** had “severe” ME/CFS, which means that the patient is mostly **bedbound**.
- **1%** had “very severe” ME/CFS, which means that the patient is **bedbound and in need of care**.

# Serbia: ME/CFS Triggers

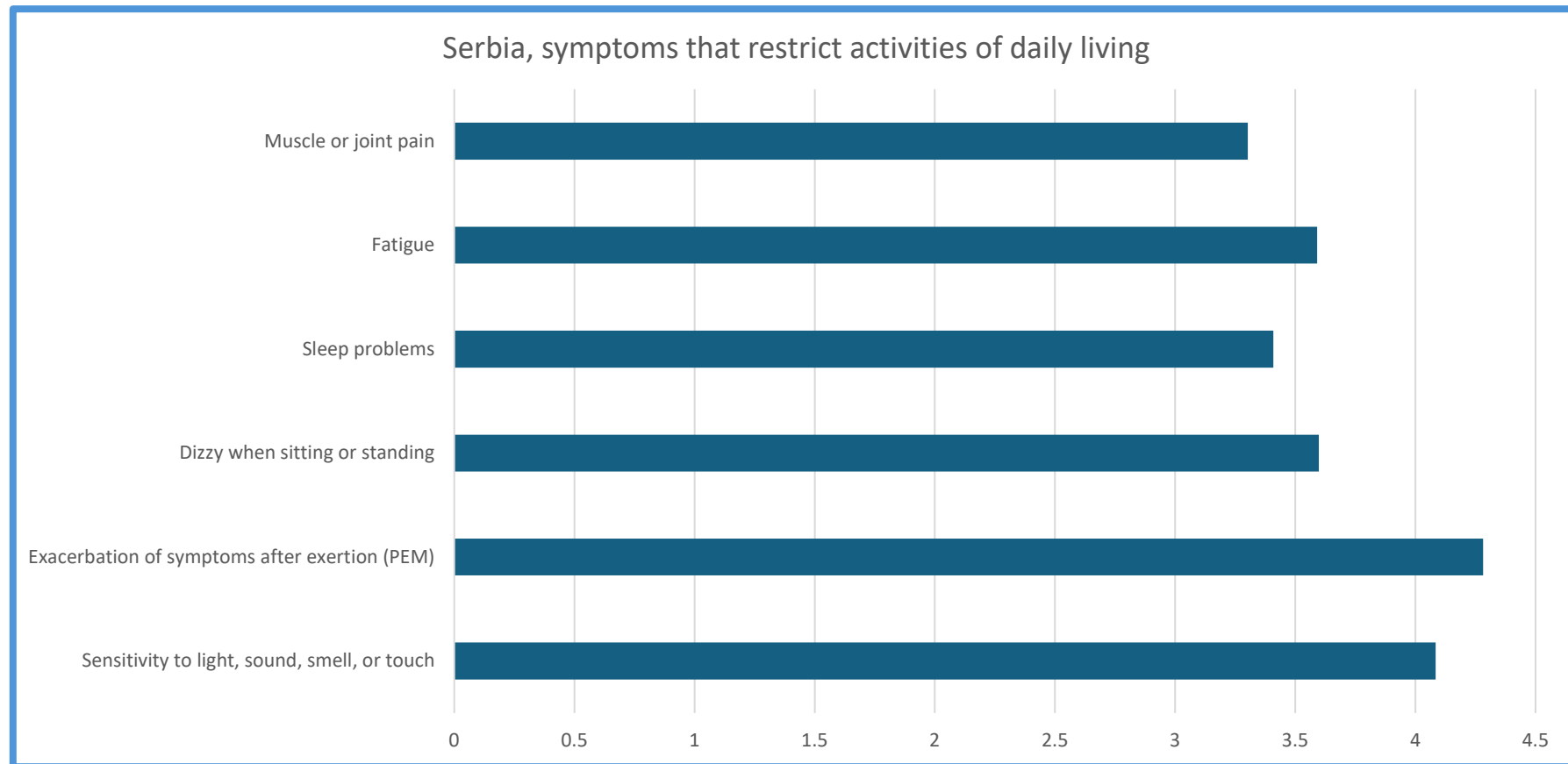
Serbia is the only country that reported the onset of ME/CFS was not mainly associated with **infectious disease**. The trigger most often reported was **traumatic life events/stress**.



# Serbia: Symptoms that limit daily activities

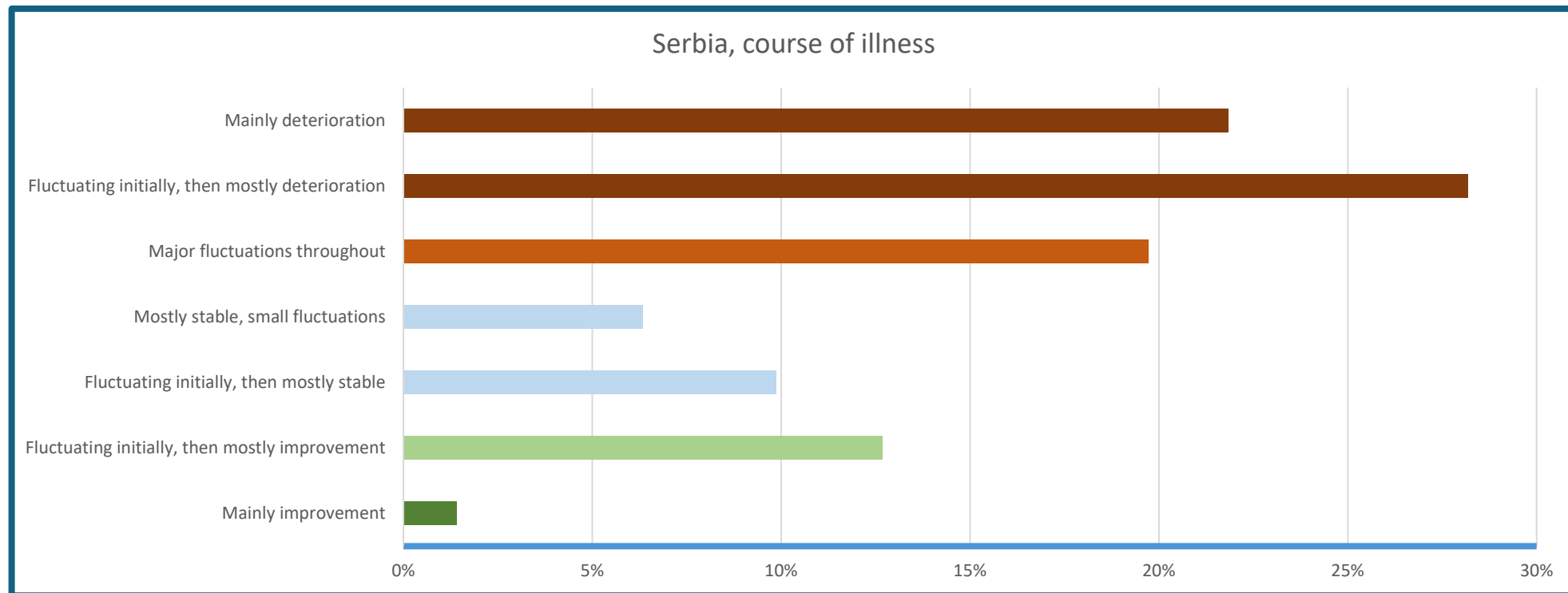
The 3 main symptoms reported were **Post-Exertional Malaise (PEM); Sensitivity to light, sound, smell and touch; and Fatigue.**

➤ This is another reason why patients need to remain in the **protected environment of their homes.**

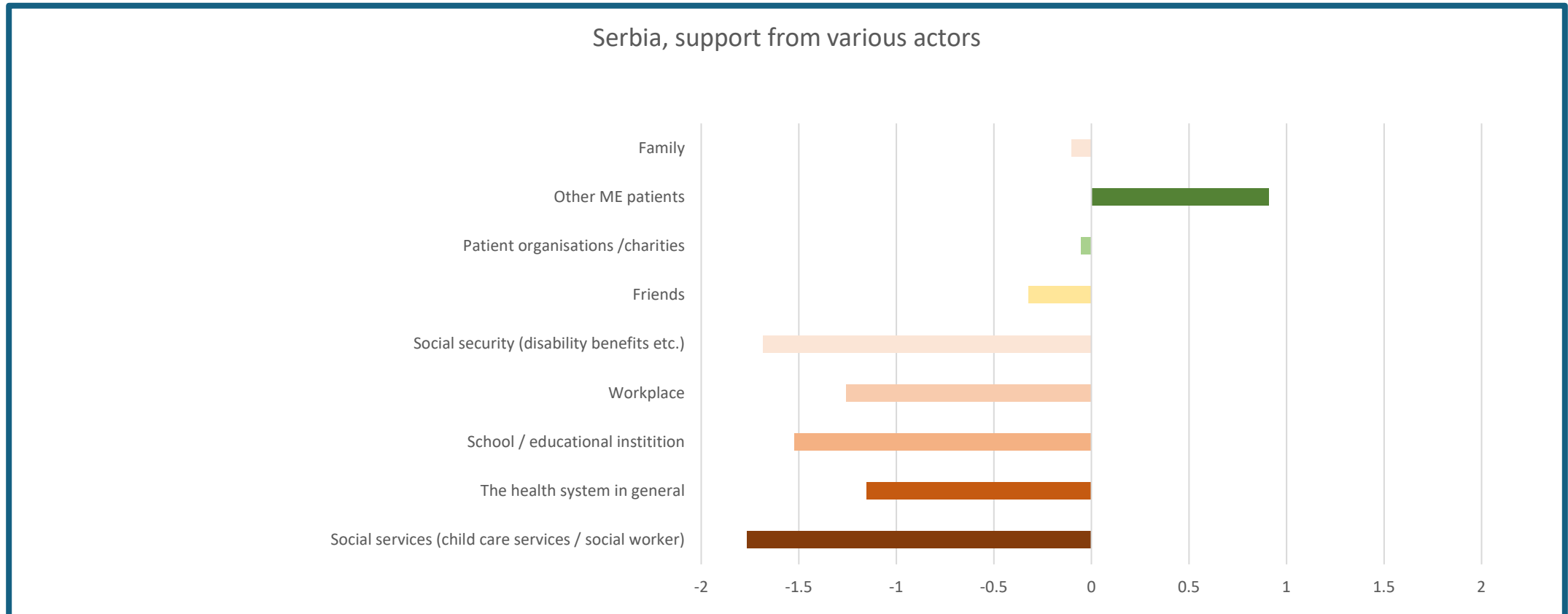


# Serbia: Symptom deterioration and fluctuation

**70% of respondents had experienced deterioration or major fluctuations in their symptoms until now**, 16% said they were mostly stable, and 14% had experienced mainly improvement.



# Serbia: Patient support comes from other patients





WORLD  
HEALTH DAY

EMEA Pan-European ME Patient Survey



[europeanmealliance.org/surveyoverview](http://europeanmealliance.org/surveyoverview)

## Main conclusions of the EMEA Survey

- People have **profound disability levels and unmet needs.**
- **Access to medical care and social support varies across Europe.**
  - This results in both a general but dangerous neglect of the illness
  - Different approaches by national health authorities, impact the course of illness and disease outcomes.
- There is an urgent priority to recognise ME/CFS as a **serious physical illness** and provide better medical care, financial support, and social services, and pursue a fully funded long-term strategy of **biomedical research** into this disease.

# Healthcare systems are failing sufferers

The EMEA survey revealed that **healthcare systems are failing sufferers.**

- Three out of four people **(74%) felt that they received little or no health care support.**
- One out of 8 (12%) had good or very good support.

# Pacing: A beneficial strategy

The survey found that **'pacing', or remaining within your energy limits,** was the most beneficial strategy for managing the condition.

- Learning 'pacing' through early diagnosis helps avoid overexertion and improves prognosis.
- We can help patients not to overexert themselves by providing them with social assistance.

# Harmful therapies: Graded Exercise Therapy

**Because symptoms worsen due to Post-Exertional Malaise** – which is the worsening of symptoms after even minimal ‘activity’ – therapies involving ‘activity’ or ‘fixed increases in activity’ – such as **Graded Exercise Therapy** – were **reported by almost 50% of respondents as deteriorating the course of their illness.**

- Therefore, lack of **diagnosis or mis-diagnosis must be avoided**, so that people are not prescribed therapies that can worsen their symptoms.

# Harmful therapies: Biopsychosocial Model

**Patients strongly rejected the Biopsychosocial (BPS) model,**  
and considered it a failed and harmful approach to ME/CFS.

# Biopsychosocial Model

- **ME/CFS is psychological** and linked to dysfunctional illness beliefs, a pathological focus on symptoms, fear of activity, and resulting deconditioning.
- **Cognitive Behavioural Therapy (CBT)** is often prescribed to help patients change their 'false' beliefs.
- The cure is teaching the patient to **ignore symptoms**, to **“push through”** and to **follow an exercise program**, such as Graded Exercise Therapy.
- The model **places the responsibility for both having ME/CFS, and for recovery from it, squarely on the patient**, leading family and friends to refuse to provide the patient with any assistance – and causing trauma to patients and the worsening of their symptoms.

# ME/CFS: A medical scandal



George Monbiot, journalist for the UK publication 'The Guardian' said that **ME/CFS is the biggest medical scandal of the 21<sup>st</sup> century** in his [article](#) on 12 March 2024:

*“For decades, patients with ME/CFS have been told they can make themselves better by changing their attitudes.*

*Long after this approach was debunked in scientific literature, clinicians who championed it have refused to let go. They continue to influence healthcare systems, governments and health insurers. And patients still suffer as a result.”*

# Stigma and Disbelief

ME/CFS patients suffer not only from the disease, but also from stigma and disbelief spread by **flawed opinions and misinformation** that:

- **ME/CFS is psychosomatic**, and due to the person's false belief that they are ill.
  - Just because a diagnostic biomarker has not yet been found, does not mean an illness does not exist.
- ME/CFS eventually 'burns out' and **people recover**.
  - The EMEA survey reported only about 7% of respondents improved over time, and that symptoms can last a lifetime.
- **Sufferers are lazy**, liars, and malingerers who do not want to work.
  - How has it become morally and ethically acceptable to negatively stereotype millions of people, all reporting similar symptoms, and living for years in such a debilitating condition?



# Human Rights Violations

1. **People's human rights are being violated** due to disbelief, stigma, social barriers, and discrimination, leading to denial of receiving personal and financial assistance and to obtaining the best attainable health.
2. **The United Nation's call for universal health coverage is not meaningful** because the health system has little to offer people other than the management of some of their severely disabling symptoms.
3. Many people's **disabilities are not recognized** because they lack a diagnosis. Even if they have a diagnosis, their disability may not be recognized by their national competent authority. **This leaves them outside the legal and social protection of the United Nations Convention on Rights of Persons with Disabilities.**

# WHO Europe video in support of ME/CFS

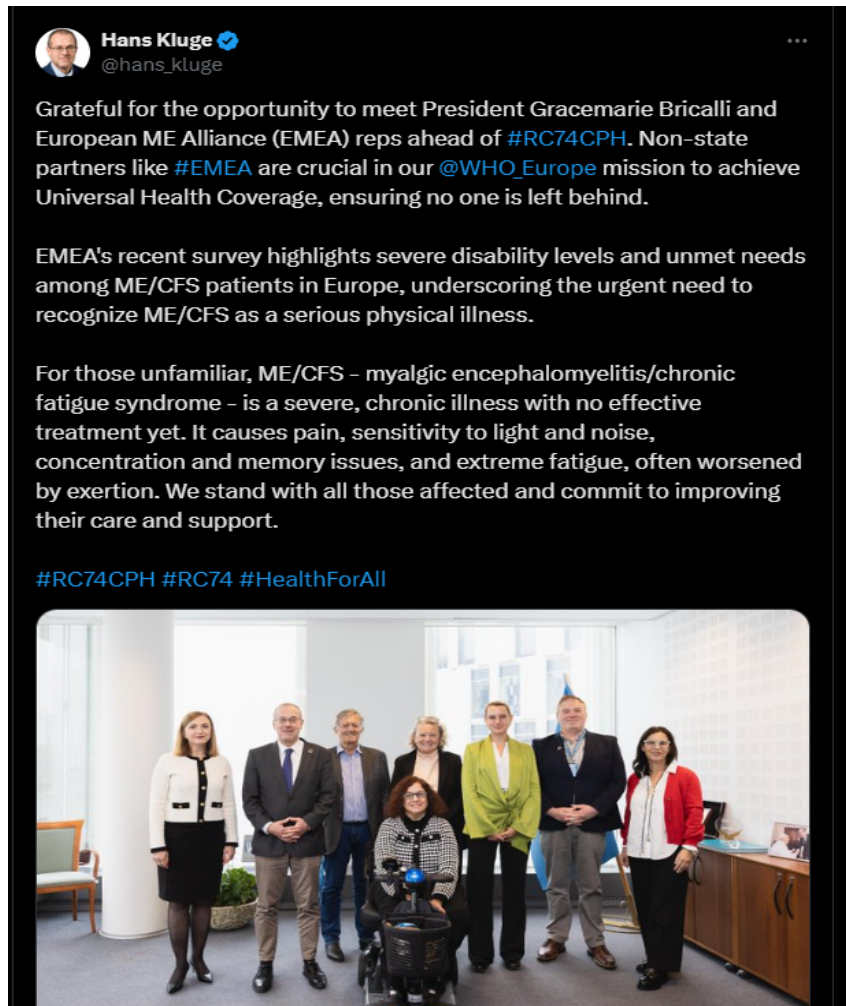


EMA received a video from Dr. Cathal Morgan, WHO Europe Technical Officer for Disability Services.

**Dr. Morgan urged governments to recognize ME/CFS as a physical illness as defined by WHO, and provide assistance to patients NOW.**

Video for the EMA-supported International ME Research Conference in June 2024.

# EMEA meeting with WHO Europe



On 28 October 2024, EMEA met with **Dr. Hans Kluge, Regional Director of WHO Europe**, who said that:

- 1. Disbelieving patients is one of the worse things that can happen to them.**
- 2. We must work to restore people's trust in the healthcare system.**
- 3. He pledged to leave no person with ME/CFS behind.**

**Next steps:** EMEA and WHO Europe will **work together with interested Member States** to identify action points to move the collaboration forward.

Tweet: [https://x.com/hans\\_kluge/status/1850900082071052597](https://x.com/hans_kluge/status/1850900082071052597)

EMEA statements at RC74: <https://www.europeanmealliance.org/emea-news-who-e-2410.shtml>

# European Parliament Meeting



## European Federation of Neurological Associations

3,020 followers

5h • Edited • 🌐

**Gracemarie Bricalli**, President, European ME Alliance (EMEA) explains that there is an urgent need to invest in **#research** for ME/CFS. The condition has no biomarkers which makes diagnosis difficult. Without diagnosis there is no access to supports or services and people are denied basic human rights. Criteria for **#disability** does not measure the extreme severity of this condition.

**#BHNCevent #neurology  
#MyalgicEncephalomyelitis**



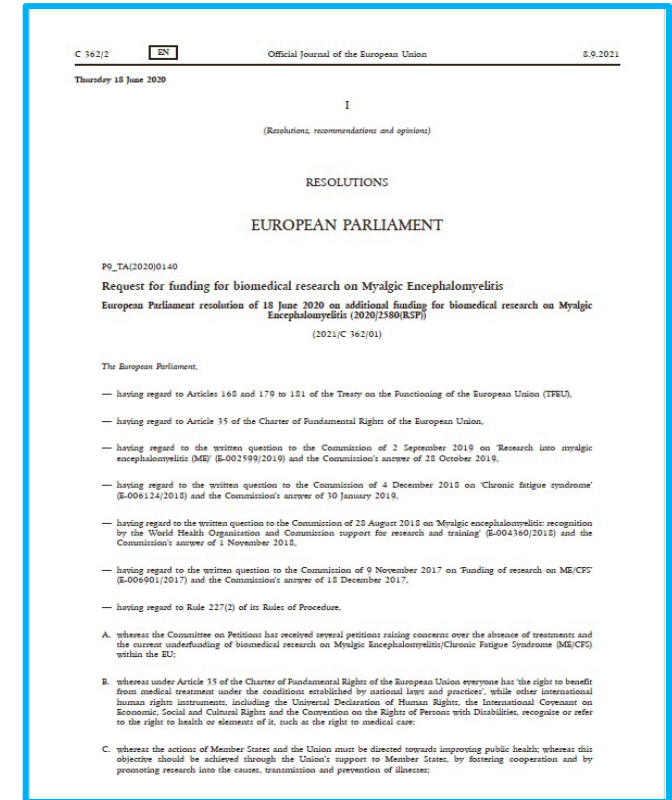
On 22 November 2024 EMEA spoke at the European Parliament meeting of the **MEP Interest Group on Brain Health and Neurological Conditions**.

The event was hosted by **MEP Romana Jerkovic, Croatia**, who is now encouraging MEPs to work with patient groups to understand how to address neurological conditions, like ME/CFS.

# EMA asked MEPs to request an update on the implementation of the 2020 European Parliament Resolution on ME/CFS (2020/2580(RSP)) (2021/C 362/01)

The Resolution calls for:

- Additional **funding for biomedical research.**
- Information campaigns among health professionals and the public to **alert the population to the existence and symptoms of ME/CFS.**
- **Targeted training for public authorities, healthcare providers and officials in general.**



# What we need to do nationally

- Develop a **national strategy on ME/CFS**.
- Include the latest scientific evidence in **medical curricula**.
- Ensure an **ME/CFS disease registry** that uses WHO ICD Codes and SNOMED Clinical Terms (Systematized Nomenclature of Medicine Clinical Terms).
- Request national and EU authorities to provide **designated research grants for ME/CFS**.
- Develop **Centers of Excellence** for ME/CFS, possibly within existing research parks with multidisciplinary teams.

# What we need to do at the EU and global levels

- Request your MEPs to **join the MEP Interest Group** on Brain Health and Neurological Conditions.
- Request your MEPs to **call for an EU Regulation** for a European strategy on ME/CFS.
- Request the Minister of Health to **propose action points** on ME/CFS in the [WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders](#).

# Our united moral and ethical responsibility to patients

- We must provide patients with a **national ME/CFS contact person**, who has the legal authority to intervene on their behalf, and protect their human rights.
- **We must alert everyone about the disease**, to avoid unintentional harm to patients due to lack of knowledge about the disease.
- We must develop **moral and ethical guidance** on how to interact with people with 'invisible' illnesses, and make sure we **provide for patients' basic needs, alleviate unnecessary suffering, and leave no one behind.**



**Thank you for your attention and all you are doing to help people suffering from ME/CFS!**

For more information please visit:

[www.europeanmealliance.org](http://www.europeanmealliance.org)

or contact EMEA at:

[info@europeanmealliance.org](mailto:info@europeanmealliance.org)

