

Invisible Issues: Bridging the gap between the perception of neurological conditions and their true impact

MEP Interest Group on Brain Health and Neurological Conditions

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I have no declarations of interest.



European ME Alliance (EMEA)

- Voice of people with myalgic encephalomyelitis (ME or ME/CFS)
- 18 member countries and growing
- Advocating for biomedical research
- Supporting the European ME Research and Clinicians Groups, and an international research conference
- Accredited by WHO Europe
- Board Member of the European Federation of Neurological Associations
- Member of the European Disability Forum
- Member of the European Patient Forum

ME – A severely disabling physical disease

- A severe, long-term, complex, chronic, systemic disease.
- Characterized by profound and persistent fatigue, autonomic, neurocognitive, immunological, and energy metabolism dysfunction symptoms.
- Can affect anyone at any time.
- The [European Parliament's 2020 EU Resolution on ME/CFS](#) reports there are **2 million** people afflicted in Europe and **24 million** globally – numbers which they estimate to be 10% of those affected = **240 million worldwide**.

Worst Quality of Life

A 2015 [health impact study](#) by the Danish 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.

Stigma and Disbelief

People suffer **stigma and disbelief spread by flawed opinions and misinformation** that:

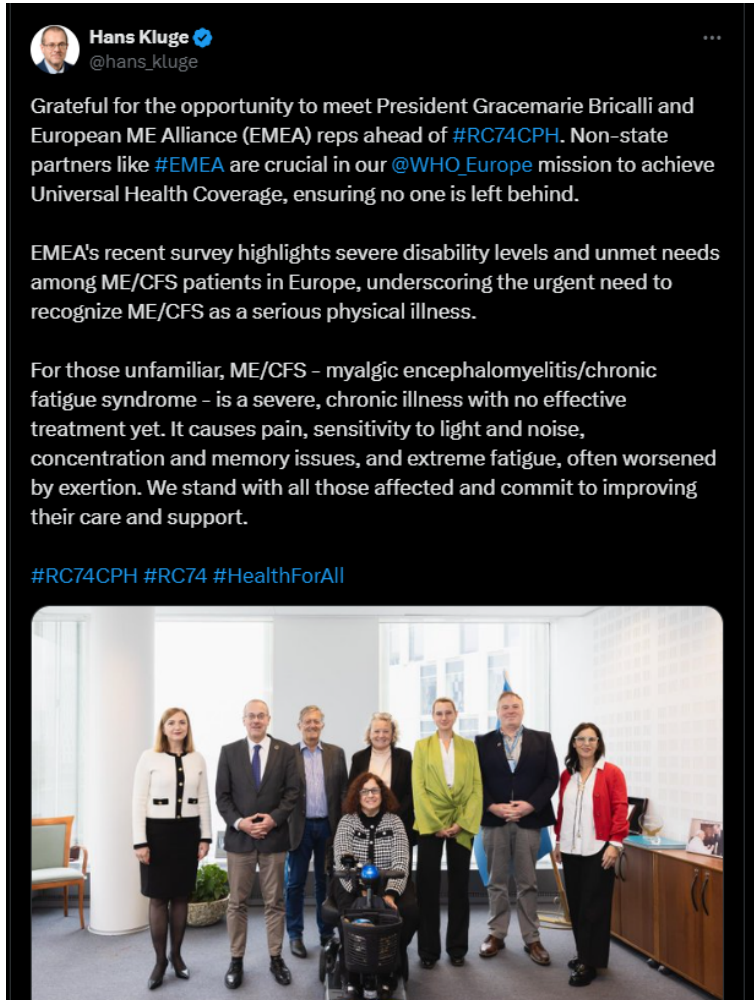
- ME/CFS **does not exist or is psychosomatic**, and due to the person's false belief that they are ill.
- ME/CFS eventually 'burns out' and **people recover**. An [EMEA survey](#) of 11,000 sufferers reported only about 7% improved over time.
- **Sufferers are lazy**, liars, and malingerers who do not want to work.

Question: How has it become culturally and morally acceptable for decision-makers, without expertise in ME/CFS, to tell people suffering from its severely disabling symptoms that they are healthy or mentally ill – leading to **lack of diagnosis, mis-diagnosis, and prescription of therapies that can worsen their symptoms?**

ME - A biological illness with no diagnostic biomarkers or treatments

- ME/CFS has been recognized as a neurological and post-viral syndrome by the **World Health Organization** since 1969.
- The **US Centers for Disease Control and Prevention** define ME/CFS as **a biological illness**. People may not look sick but they are unable to perform their normal activities.
- The **2015 US Institute of Medicine Publication** states that despite substantial efforts by researchers to better understand ME/CFS, there is **no known cause or effective treatment**.

WHO Europe statement of support for ME/CFS



https://x.com/hans_kluge/status/1850900082071052597

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

- 1. Patients being disbelieved 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.**

Read [EMEA's 4 statements](#) at the 2024 WHO Europe RC74.

Next steps: EMEA and WHO Europe will work together on identifying action points to move the collaboration forward.

WHO Europe video in support of ME/CFS



For the EMEA-supported [International ME Research Conference](#) in June 2024, EMEA received a [video from Dr. Cathal Morgan, WHO Europe Technical Officer for Disability Services](#).

“We know that research and treatments will take time, even years, to develop and implement, and in the meantime, **governments must address the urgent ethical question of how to provide assistance today to ME/CFS patients** with ‘invisible’ or ‘medically unexplained symptoms’, both to respect their basic human rights and their rights under the UN Convention on the Rights of Persons with Disabilities”.

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.
2. **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. This is the result of the lack of research funding to identify biomarkers and curative treatments.
3. Many people's **disabilities are not recognized** because they lack a diagnosis, and their disability is not recognized by their national competent authorities. This leaves them outside the legal and social protection of the UN Convention on Rights of Persons with Disabilities.

A day in the life of an ME/CFS sufferer



10%

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. Most of the day there is only the ceiling to look at since you do not have the energy to get out of bed or do anything.
5. 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 who try to organize medical appointments at home because hospitals have no dedicated rooms that protect ME/CFS patients.
6. You feel vulnerable, traumatized, isolated, and defenseless.
- 7. REPEAT.**

Many people's **symptoms** are self-reported and '**invisible**'



- **Intolerance** to light, sound, and smell.
- **Brain fog**, inability to process information, to read or write, watch TV or listen to music.
- **Profound weakness**, resulting in need to spend all day in bed, in a dark and quiet room.
- **Intolerable pain**.
- Some **very severely affected people cannot talk**, have to be tube fed, and are intolerant to human touch.

Defining Symptom: Post-Exertional Malaise (PEM)

- **People often have difficulty describing core symptoms like PEM**, which many healthcare professionals are not familiar with.
- [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, sometimes leading to a relapse.*
- **PEM makes a person's ability to function unpredictable.**

Consequences

- Most countries lack ME/CFS specialists, resulting in **non-ME/CFS specialists telling people they are physically healthy or psychosomatic.**
- Many sufferers depend on family and friends for almost everything, because **they are not able to take care of themselves** or their families.
- Many are **not able to work** and rarely receive social or disability insurance benefits, creating **financial hardship and generational poverty.**
- Some sadly even **resort to suicide** because the pain, the stigma, and their situation which has no legal protection, seems hopeless and unbearable.

Millions missing – Costing billions

Not only are **millions of people missing** from school, from work, and from everyday activities.

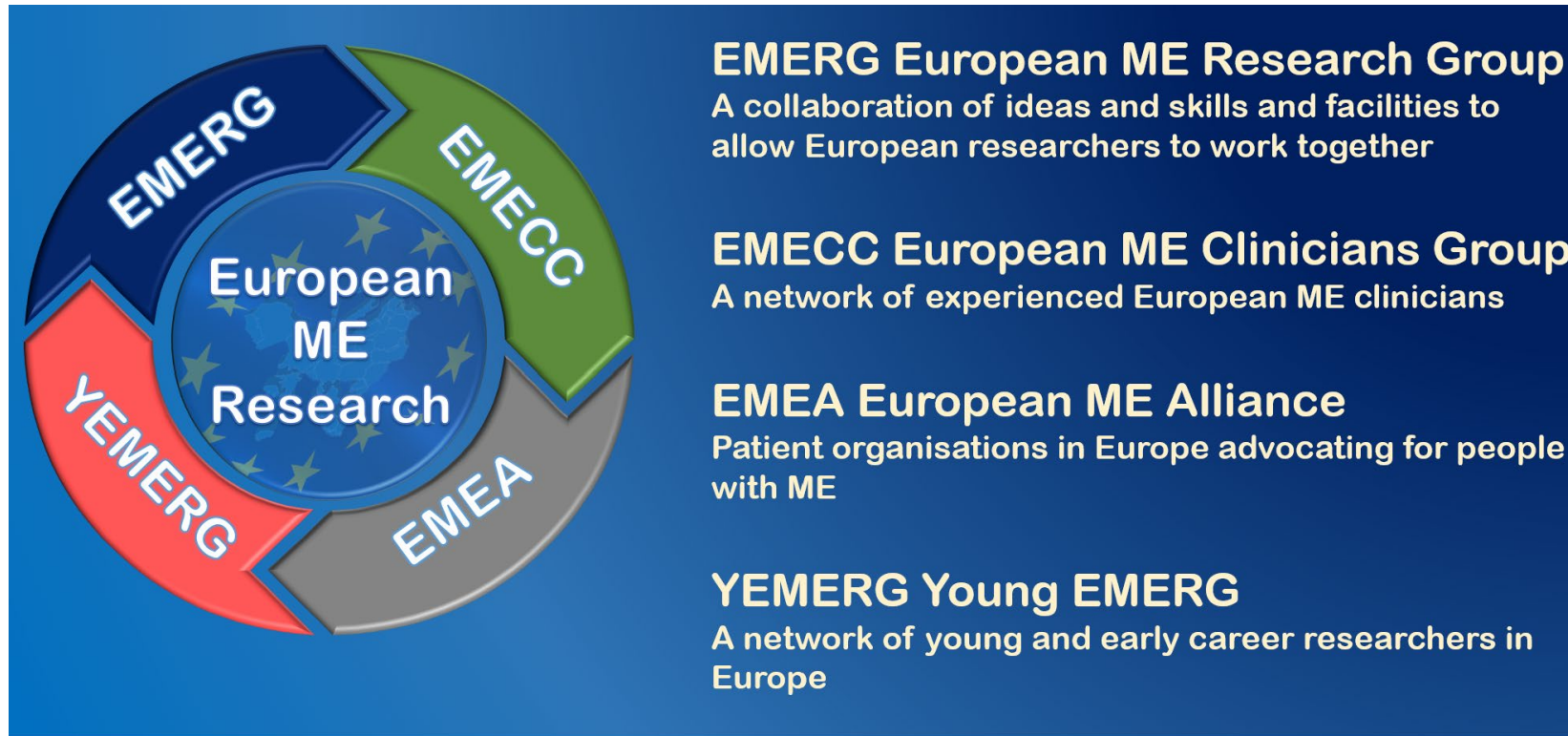
There are also **millions missing in biomedical research funding**, despite the major burden the disease places on patients, families, health systems, and national economies.

The direct and indirect **economic costs** of ME/CFS to society are estimated to be approximately over **\$18 to \$24 billion annually** ([Jason et al., 2008](#)) – **funds that could be invested into cultural awareness about the disease and biomedical research.**

What EMEA is doing

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

We do not have the resources to do this alone. We need your help, and we need it now!



What you can do NOW!

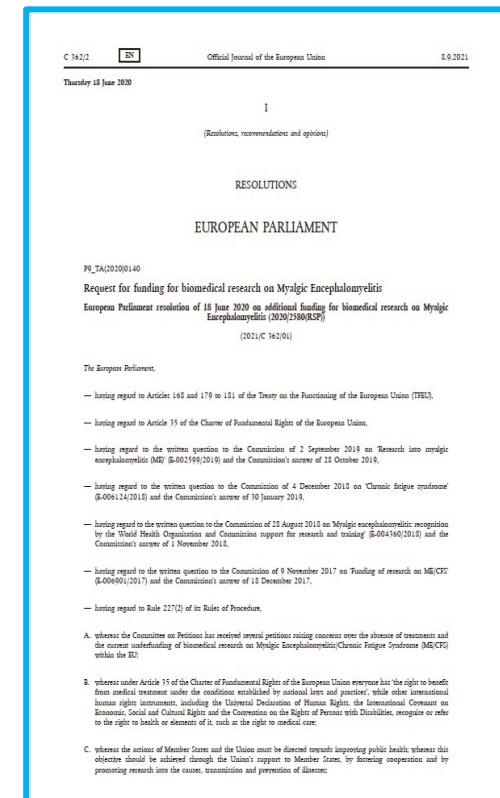
Call your Minister of Health and agree to immediate action to protect and relieve the suffering of people suffering from **ME/CFS**, because it will take time to implement a European Parliament Resolution and develop a European Strategy on ME/CFS, which is what we are calling for.



Request an update on the implement 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 and awareness-raising campaigns among health professionals and the public in order to **alert the population to the existence and symptoms of ME/CFS**.
- Specifically **targeted training** should be provided to raise awareness among **public authorities, healthcare providers and officials in general**.



Propose a European Strategy for ME/CFS

Call for a Parliamentary Regulation to develop a European and national strategies which should include:

- **Official recognition of ME/CFS as a somatic illness as defined by the WHO.**
- Implementing **WHO's ICD Codes for ME/CFS** in national health systems.
- Ensuring **sufferers are not marginalized and stigmatized**, and they receive timely physical, financial, medical, and social support.
- Including the latest scientific evidence in **medical curricula**.
- Developing **disease registries** utilising the most up-to-date diagnostic criteria.
- Providing **adequate funding for biomedical research**.
- Rapidly advancing development of **Centers of Excellence**.
- Including **action points on ME/CFS** in the

[WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders.](#)

Thank you!

For more information please visit:

www.europeanmealliance.org

Or contact EMEA at:

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