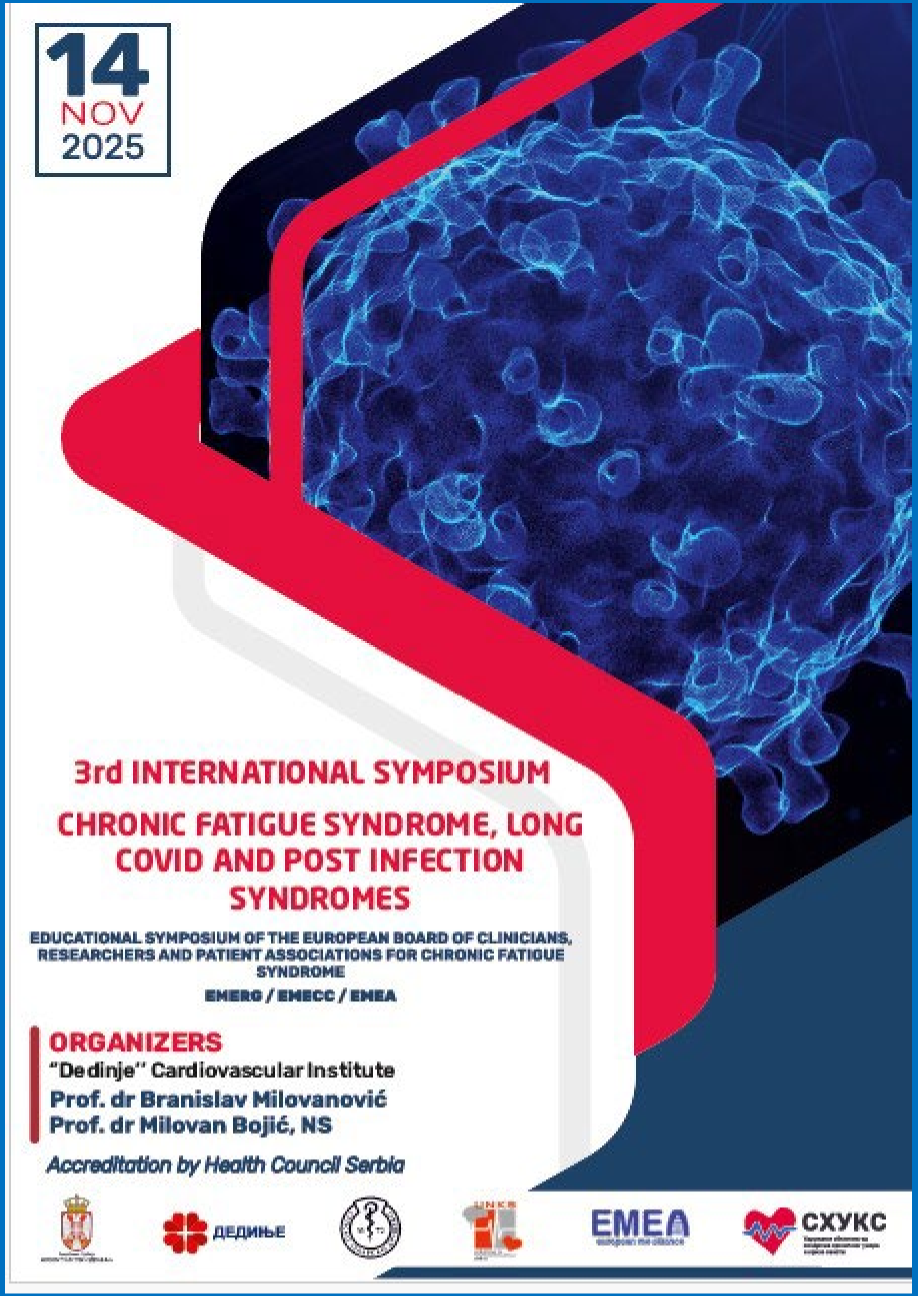

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NOV
2025

3rd INTERNATIONAL SYMPOSIUM

CHRONIC FATIGUE SYNDROME, LONG COVID AND POST INFECTION SYNDROMES

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

EMERG / EMECC / EMEA

ORGANIZERS
"Dedinje'' Cardiovascular Institute
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Accreditation by Health Council Serbia

Denying the existence of ME and its disabling symptoms: The impact on patients and what clinicians can do

Gracemarie Bricalli
President of the European ME Alliance (EMEA)
www.europeanmealliance.org

European ME Alliance (EMEA)

- Founded in 2008.
- Voice of people with myalgic encephalomyelitis (ME, sometimes referred to as ME/CFS).
- Advocate for patients rights and biomedical research for better patient outcomes.
- 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

European framework for ME 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 research conference by our UK charity, Invest in ME Research.

EMERG European ME Research Group
A collaboration of ideas and skills and facilities to allow European researchers to work together

EMECC European ME Clinicians Group
A network of experienced European ME clinicians

EMEA European ME Alliance
Patient organisations in Europe advocating for people with ME

YEMERG Young EMERG
A network of young and early career researchers in Europe

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www.investinme.eu

- https://emerg.eu/euromeresearch.shtml
- https://www.emerg.eu/em-team.shtml
- https://www.investinme.org/index.shtml

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Strategic Collaboration

EMEA strategically collaborates with:

- WHO Europe, as an accredited Non-State Actor. WHO recognizes ME/CFS as a physical neurological illness since 1969
- European Federation of Neurological Associations, as a Board member
- European Disability Forum, uphold UN Convention on the Rights of Persons with Disabilities
- European Patient Forum
- NCD Alliance

ME destroys millions of lives

Across Europe, an estimated two million people live with ME — and **an estimated 240 million worldwide**, according to the **2020 European Parliament Resolution on ME/CFS** which calls for national training, awareness campaigns, and increased funding for biomedical research.*

With Long Covid patients reporting similar symptoms to ME/CFS, the numbers are increasing exponentially.

* https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52020IP0140

Harm caused by the disease

While we wait for research to identify biomarkers and curative treatments **patients suffer daily and need assistance *now.***

Their ability to function is unpredictable due to the defining feature of ME which is ‘**post-exertional malaise**’ **(PEM)**.

PEM is not ordinary fatigue — it is a **systemic physiological collapse** affecting multiple bodily systems, including neurological, immune, metabolic, and cognitive functions, as well as cardiovascular and muscle systems.

To avoid PEM, patients need to **conserve energy and ‘pace’** themselves. **To be able to ‘pace’ patients need other people to take over household and administrative tasks.**

Harm caused by lack of knowledge about ME

Our recent **EMEA Pan-European Patient Survey***, with over 11,000 respondents, revealed that ME patients are still routinely **misdiagnosed, dismissed, or subjected to harmful treatments due to lack of clinical knowledge**.

Despite international consensus statements, diagnostic and treatment guidelines, thousands of scientific publications, and patient testimonials:

- Patients are told to ignore their symptoms and **'push through'.**
- Social service systems **deny assistance** to patients.
- Patients are told they are **healthy enough to work** despite not being able to get out of bed.
- Families are told not to help their loved ones because they **just 'think' they are ill**.

* https://www.europeanmealliance.org/emea-pan-european-survey-pr-uk.sht

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Harm caused by misinformation about ME

A justification for denying patients financial and social assistance, long-term medical care and rehabilitation has been **framing ME as a psychosomatic or functional illness** (biopsychosocial model), **which negates the need for investment in biomedical research**.

To scientifically and ethically protect patients from preventable harm, **we must critically examine how financial incentives and outdated and debunked psychiatric paradigms have combined to deny ME's biological reality** and to undermine the right of patients to the dignity and healthcare they deserve.

Just because a diagnostic biomarker has not yet been identified does not mean a physical illness does not exist.

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Harm caused by denial that ME symptoms are disabling

When people do not know enough about ME, and **do not take the time to educate themselves, they deny that ME symptoms are disabling**

- Patients are told they are **liars or malingerers who do not want to work**.
- Patients are denied financial support causing **economic hardship and poverty**.
- Patients are **denied the personal assistance they need to be able to ‘pace**’ and respect the biological limitations of their illness.
  - This forces them to over-exert themselves to do basic activities just to survive, **causing an increase in disability levels**.

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Harm caused by denial that ME symptoms are disabling - continued

- There is **no accommodation for patient sensitivities**, such as those to light, sound, and smell.
- There is **no provision of office or hospital rooms** that are quiet, dimly-lit, fragrance-free and allow patients to lie down when necessary.
  - These are all accommodations **that avoid triggering PEM and physical 'crashes'** (post-exertional symptom exacerbation).
  - These crashes can be so severe that an ME patient becomes unable to communicate, to process information, and is bedbound for days or weeks.

Patients know from experience the risk is great that they may never recover from a 'crash'.

Harm caused by human actions

Unlike for other disabilities:

- These are **avoidable human actions** that **cripple people with ME**.
- Harm caused by other people **increases the progression of the disease AND a patient's disability level.**

We do not know of any other disease where people experience such harmful neglect and disbelief - and we do not understand how this has become morally acceptable in our culture.

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The harm of misunderstanding ME is profound and lasting

- Families give up jobs to provide full-time care, creating financial crisis and **generational poverty.**
- **Parents are falsely accused** of child abuse and neglect.
- **Children are removed from their homes** and forced into foster care or psychiatric units, causing irreparable harm to their health.
- **Requests for euthanasia** are far higher among ME patients than the general population because suffering, isolation, stigma, and lack of support make life unbearable.

Instead of helping people to die, we must help them to live – to live with dignity, better quality of life, and hope.

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Harm caused by lack of patient support

Patients’ bodies do not produce enough energy. This leaves many **unable to perform everyday activities or care for themselves.**

Without support from a healthy person,

- **Patients** are forced to use more energy than their bodies can reproduce, causing them to **become increasingly disabled**.

With support from a healthy person,

- **Patients are able to 'pace'** and ensure that they do not use more energy than their bodies can reproduce. This helps them to avoid the worsening of their symptoms, giving them a chance to stabilize and possibly begin to recover.

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Harm caused by lack of patient support_continued

Many people experiencing disabling symptoms due to ME are aware of it because there is a huge amount of information online.

Many people report that **the level of support received had a significant impact on their health,** either improving their health or causing their health to deteriorate to the point of rendering them severely disabled and bedbound for years.

Unfortunately, many people report being **denied support to be able to ‘pace**’.

- This makes them feel discriminated against
- It unnecessarily augments their disability level and **leaves them unable to defend themselves and speak out against the harm being done to them.**

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Five ways Clinicians can support and protect their patients

Think of the 5 fingers on your **‘helping hand’** as representing five ways to respect your patients’ human right to the best attainable health possible.

1. **Educate yourself** about ME/CFS and **diagnose early** using International Consensus Criteria*, NICE guidelines*, etc.
2. **Explain PEM and teach ‘pacing’** and energy conservation, in addition to **supporting disability and social assistance claims** so people receive the support they need.
3. **Provide information** for families, carers, and teachers, and **raise awareness** among your medical colleagues.
4. **Accommodate sensitivities** with quiet spaces and telemedicine for those too ill to travel.
5. **Advocate for change** in policy and funding for biomedical research.

*https://onlinelibrary.wiley.com/doi/10.1111/j.1365-2796.2011.02428.x
*https://www.nice.org.uk/guidance/ng206

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Centers of Excellence for ME exist

1. **In the UK**, the EMEA-supported ME/CFS Centre of Excellence at the **Quadram Institute** is a hub for European research and treatment.*
2. **In Iceland**, since 2024 the **Akureyri Clinic** provides integrated care for ME and Long COVID.*
3. **In Norway**, the **Røysumtunet**, a private, non-profit institution, provides care for people with severe conditions, including a specialized service for severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).*

* https://quadram.ac.uk/targets/me-cfs/
* https://island.is/en/o/sak/news/akureyri-clinic-formally-founded
* https://roysumtunet.no/Avdeling-ME

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Swiss national strategy for ME/CFS and Long Covid

Every country needs a **comprehensive coordinated national strategy on ME/CFS** so that health professionals and decision-makers are not isolated or working in silos.

Switzerland is taking the lead. On 18 September 2025, the government decided to develop a national strategy for ME/CFS and Long Covid beginning in 2026.*

* https://www.europeanmealliance.org/news-Q32025-003-2.shtml

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Remember

- **ME patients cannot ‘pace’ alone.**
- **Helping them pace, and avoid triggering PEM, is helping them survive.**
- **Providing them with the support they need is not secondary to medicine — for them it *is* medicine.**

We count on your commitment to **work with EMEA** so we can improve the quality of life of ME patients today, as researchers work towards finding a cure.

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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

or contact EMEA at: info@europeanmealliance.org

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