A Shocking Indictment of European Research and Healthcare Policies for Myalgic Encephalomyelitis

Sunday 7 April, 2024

Press Release from the European ME Alliance
Embargoed Until 7 April 2024

A Shocking Indictment of European Research and Healthcare Policies for Myalgic Encephalomyelitis

[Stockholm, 7 April 2024]

The European ME Alliance (EMEA) today releases the findings of a comprehensive survey shedding light on the distressing state of Myalgic Encephalomyelitis (ME, sometimes referred to as ME/CFS in some countries *) patients across Europe.

The survey, conducted among more than 11,000 people with ME/CFS in Europe, presents a stark indictment of European and national policies for neglecting the ongoing and protracted suffering of millions of patients and their families impacted by this inadequately studied disease. Therefore, we call on governments, healthcare providers, research agencies, healthcare policymakers, healthcare ministers, politicians, and European organisations to work with EMEA and take action to address the unmet needs of people with ME/CFS.

The results from the survey underscore a concerning lack of recognition and support for individuals grappling with this debilitating disease and paints a stark picture of the overwhelming challenges faced by people with ME/CFS in Europe.

The survey reveals that healthcare systems are failing them, with three out of four patients (74%) feeling that they received little or no health care support, while only 1 out of 8 (12%) had good or very good support.

Key findings from the survey reveal profound disability levels and unmet needs among ME/CFS patients, highlighting the urgent necessity for healthcare systems to acknowledge ME/CFS as a severe physical illness and enhance medical care, financial support, and social services and pursue a fully funded long-term strategy of biomedical research into this disease.

Furthermore, the survey revealed significant disparities in access to medical care and social support across Europe, with varying approaches by national health authorities influencing the course of illness and disease outcomes.
The failure of healthcare systems to address adequately the needs of ME/CFS patients has serious consequences, as highlighted by the survey results.

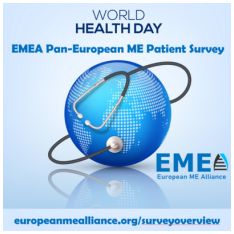
While no objective diagnostic tests for ME/CFS, verified biomarkers, curative medications or treatments for ME/CFS exist, healthcare support nevertheless matters for the management of the symptoms and the improvement of functional capacity, and thus the course of illness. Early diagnosis, activity management (pacing) and avoidance of over-exertion (Post-exertional malaise (PEM) are key to reducing the risk of progression to severe disease.

The survey found that keeping activity levels within the energy envelope - commonly known as pacing - emerged as the most beneficial strategy for managing the condition. Conversely, activity-based therapies were found to exacerbate symptoms, with almost half of respondents reporting a deteriorating course of illness as a result.

The survey strongly refutes the Biopsychosocial (BPS) model, labelling it as a failed and harmful approach to ME/CFS. Therapies involving fixed increases in activity were shown to worsen symptoms, emphasising the importance of pacing and avoidance of over-exertion.

Persistent myths exist about ME/CFS being an illness that gradually ‘burns out’ and that patients recover over time. Though some patients may indeed improve over time, most do not. Symptoms are severe and can last a lifetime.

Media:



Related Sectors:

Charities & non-profits :: Government :: Health :: Medical & Pharmaceutical ::

Scan Me:

A lack of recognition of the disease as a serious physical illness in many countries denies patients a timely diagnosis and access to adequate social and welfare benefits necessary for basic survival, violating their basic human right to the best available health.
The survey reveals that long delays in the diagnosis from disease onset are common, averaging 6.8 years across Europe with large variations across countries

ME/CFS must be viewed as a chronic condition as this perception has major implications for welfare benefits and other services provided.
Early diagnosis, activity management (pacing) and avoidance of over-exertion are key to help preventing progression to severe disease.

As high-quality prospective studies on typical courses of illness are lacking, large patient surveys such as this one may provide the best information available.

The dire situation for most ME/CFS patients across Europe is, in part, the result of both ignorance and lack of knowledge among health professionals, social workers, and policy makers. Yet ME/CFS has been recognised as a disease of the nervous system by the World Health Organisation since 1969.

Lack of funding biomedical research contributes to ME/CFS being categorised as a high burden under prioritised disease that urgently requires a dedicated EU strategy.

European governments must step up to fund existing, and develop new, Centres of Excellence for ME/CFS to perform a joined-up pan-European strategy of coordinated, collaborative translational biomedical research across Europe that will focus on establishing a full understanding of the disease and the development of treatments to mitigate or cure it.
EMEA has already led the way by establishing collaborative European groups for researchers, clinicians and young/early career researchers and, of course, patients. By collaborating across Europe, we can harness the best talents from the best institutions who are intent on working together.
This will assist in building the capacity of research resources within Europe that is necessary for major discovery about this disease to take place.
Importantly, it allows the continuation of research and creates the foundations for making progress in establishing European fundamental research into ME/CFS.
Now European governments must act.

EMEA also urges that a specialist discipline for ME be created in all European countries with at least one specialist clinical centre, attached to centres of excellence in each country, along with the development and implementation of a standardised diagnostic and treatment protocol.

EMEA calls on governments to perform a pan-European epidemiological study, using the most up-to-date diagnostic criteria, to determine the prevalence and cost burden of ME in Europe.
As EMEA has previously demonstrated in its ‘ME/CFS in Europe’ webinars it is entirely possible for all European countries to implement SNOMED criteria to ascertain the correct prevalence figures.

EMEA urges policymakers and healthcare stakeholders across Europe to heed the findings from the EMEA Pan-European ME Survey and take urgent action to improve the lives of ME patients.

As we celebrate World Health Day 2024, under the slogan ‘**My health, my right**’ this first-ever Pan-European survey underscores the urgent priority for healthcare systems to recognise ME/CFS as a serious physical illness and provide better medical care, financial support, and social services, as well as a fully funded long term strategy of biomedical research into this disease.

Ignorance, apathy and a lack of research toward myalgic encephalomyelitis in Europe must not be allowed to continue. Failure to act decisively now will perpetuate unnecessary suffering and neglect of people with ME/CFS – a clear abuse violation of human rights for these citizens, who should not be left behind as the world works towards achieving Universal Health Coverage to achieve the 2030 United Nations Sustainable Development Goals.

Company Contact:

European ME Alliance

T. 07759349743
E. iinfo@europeanmealliance.org

Additional Contact(s):
Gracemarie Bricalli

View Online

Additional Assets:

Newsroom: Visit our Newsroom for all the latest stories:
https://www.emea.pressat.co.uk