

# Press release: EU supports research on poorly understood diseases

Brussels, 8 December 2022

Thanks to the dedicated work of Belgian Member of the European Parliament (MEP) Pascal Arimont and colleagues, Horizon Europe will provide new funding opportunities for research on high-burden, under-researched diseases.



Belgian Member of the European Parliament Pascal Arimont (EPP)

While modern medicine has produced many spectacular breakthroughs, some diseases remain poorly understood to this day. These illnesses often cause chronic pain and debilitating fatigue for which doctors have little to offer.

A notable example is the illness Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) which affects approximately 2 million European citizens. ME/CFS is characterized by severe energy impairment, post-exertional malaise, cognitive dysfunction, and many other symptoms. It often causes severe disability and can leave patients bedridden for years.

Evelien Van Den Brink, a 38-year-old patient from the Netherlands has been living with ME/CFS for 24 years. Like many ME/CFS patients her illness started with an infection from which she never fully recovered. In the quarter of a century in which Van Den Brink has suffered from ME/CFS, scientific research has made disappointingly little headway. There are still no biomarkers, diagnostic tests, or effective treatments for the illness.



Long-term ME/CFS patient Evelien Van Den Brink

Frustrated with this lack of progress, Van Den Brink submitted a petition to the European Parliament in 2019. It demanded more awareness of ME/CFS and funds to stimulate scientific research. *“Research on ME/CFS has been stuck inside a vicious cycle”* Van Den Brink explains. *“Because the illness is poorly understood, it is not recognized as a funding priority. This makes the field unattractive for researchers and so ME/CFS remains an overlooked area in medicine. What is needed are funds to support fundamental, pioneering research so that we can finally make progress.”*

The petition received strong support from the ME/CFS community and has been signed 14.000 times. It resulted in a 2020 EU resolution on funding for biomedical research on ME/CFS that was adopted almost unanimously by the European Parliament. One of the forerunners of this resolution was Belgian MEP Pascal Arimont of the European People's Party (EPP). He founded a parliamentary interest group for ME/CFS with members from all major political groups that urged the Commission to act on the resolution.

*“ME/CFS is a condition with a remarkably high disease burden”,* MEP Arimont explains, *“it affects a lot of people and is life-changing. Patients are forced to quit their jobs or studies, and some become home- or bedbound. ME/CFS causes a lot of suffering to patients and high economic costs to our society. It is therefore of vital importance that we provide scientists with financial incentives to study the illness and discover effective treatments.”*

The importance of ME/CFS research is also highlighted by a wave of patients who developed lingering symptoms following COVID-19. A subgroup of these Long Covid patients reports symptoms that are highly similar if not identical to ME/CFS.

*“If we had invested in ME/CFS research in accordance with its disease burden, doctors might have been better equipped to help patients with Long Covid”,* MEP Arimont argues. *“We might*

*have a better understanding of the condition and better treatments to alleviate symptoms. For too long, postinfectious syndromes have remained a blind spot in medicine. Ignoring these conditions has not been a rational use of research funds.”*

Due to the continuous efforts of MEP Arimont and his colleagues, the new Horizon Europe work program 2023-2024 includes a call for research on high-burden, under-researched medical conditions such as ME/CFS. Researchers are invited to submit proposals in a two-stage process. The call provides funding for approximately 4 grants that will receive 6 to 7 million euros each. For long-term patients such as Van Den Brink, the call offers hope that one day an effective treatment for ME/CFS will be found.

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[Tackling high-burden for patients, under-researched medical conditions. TOPIC ID: HORIZON-HLTH-2024-DISEASE-03-14-two-stage.](#)

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