



EMEC

EUROPEAN ME COALITION

Press release

Scientists call for more European research on ME/CFS

Brussels, 10 June 2020 *More than one hundred scientists have signed an open letter calling for more European research into the illness Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). On 17 June, the European Parliament plans to vote on a resolution on ME/CFS research following a popular petition signed by thousands of patients and their loved ones.*

ME/CFS is a long-term, debilitating illness that causes extreme exhaustion, poor concentration and memory, unrefreshing sleep, and many other symptoms. “The most characteristic feature is a worsening of symptoms following exertion,” says Evelien Van Den Brink, a Dutch patient who has suffered from ME/CFS for twenty-two years, since the age of fourteen. Because there is no cure for ME/CFS and its pathology remains poorly understood, Evelien submitted a petition to the European Parliament, asking for more scientific research into the condition. “More science is the only way forward,” Evelien says. “I’m almost completely bed-bound and I know fellow patients who are even worse off. We cannot let another generation suffer from this horrible illness.”

The petition has been signed fourteen thousand times and resulted in the first-ever resolution on ME/CFS in the European Parliament. “These patients have been ignored for far too long,” says Pascal Arimont, one of the members of Parliament who strongly supports the resolution. “There is currently no diagnostic test for ME/CFS because we know so little about the underlying pathology. In the US, Australia, and Canada, governments have invested substantial funds in ME/CFS research. Europe is running behind, so we urgently need to take action.” An estimated two million European citizens suffer from ME/CFS.

Today, the upcoming resolution received support from an open letter signed by 115 researchers and scientists worldwide. The letter stresses that ME/CFS “has long been a neglected area in medicine” despite its high societal burden and economic costs. “ME/CFS is not rare and it is highly debilitating,” says Professor Jonas Bergquist, who recently formed the ME/CFS Collaborative Research Center at Uppsala University, Sweden. “It often starts after a viral infection and we don’t really know what the mechanisms are for post-viral fatigue. Neuroinflammation and potentially autoimmune reactions may be parts of the explanation. More research is needed so that we get a better understanding of the disease.”

“A key priority is to develop a diagnostic test for ME/CFS to increase the accuracy of diagnosis,” Dr. Carmen Scheibenbogen, a Professor at Universitätsklinik Charité Berlin and one of the first signees of the letter, explains. “We hope to get a better understanding of the disease mechanism and eventually, an effective treatment. ME/CFS is one of the great challenges for modern medicine but I’m confident that a scientific breakthrough is possible.”

The open letter and full list of signees is available at europeanmecoalition.com

Press contact: European ME Coalition

Evelien Van Den Brink evelienvandenbrink.euteam@gmail.com Francis Martin Tel: +44 7757595350 (English)