

Petition to the German Bundestag:

# Healthcare, Scientific Research and Political Support for ME/CFS Sufferers!



**We ask the German Bundestag to commit itself to the provision of healthcare appropriate to the disease severity of ME/CFS, in particular by amending § 116b SGB V [social security code] as well as through awareness campaigns.**

**Further, we ask the House to give hope to ME/CFS sufferers by investing extensively in biomedical research on their disease.**

**Finally, we ask the Parliament to stand by those affected on a permanent basis, for example by appointing a designated representative or by creating an inter-factional working group.**

## **Justification of the petition:**

ME/CFS has been classified by the WHO as a disease of the nervous system since 1969 (ICD-10: G93.3). The number of people suffering from ME/CFS (long: "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome") in Germany is estimated at around 250,000, making the disease about three times more common than HIV/AIDS. ME/CFS particularly strikes younger people. With around 40,000 minors affected, ME/CFS is not only the most common cause for long periods of school absences; the relatively early age of onset also contributes to the enormous socioeconomic costs of ME/CFS, which are calculated at EUR 40 billion annually for the EU.

ME/CFS is a neglected disease that, despite its prevalence and severity, is not part of the curriculum at any German medical school and is therefore not well known amongst physicians. According to studies, ME/CFS remains undiagnosed in more than 90% of cases even in the U.S., although there generally more attention is being paid to the disease than in Germany. However, it is probably an even more significant problem that disease severity and complexity as well as the degree of impairment of patients are usually completely misunderstood, even when ME/CFS is diagnosed correctly. The broad symptom picture of ME/CFS makes two-thirds of those affected permanently unable to work, a quarter are even unable to leave their house or bed, and according to studies, the health-related quality of life of sufferers is on average lower than that of far better-known conditions (such as lung cancer, stroke, MS). Nevertheless, the symptoms triggered by ME/CFS are often wrongly classified as mild, imaginary or psychosomatic and surmountable. As a result, sufferers receive neither appropriate medical care nor access to social security benefits in most cases. In addition, patients are still often being subjected to harmful therapy attempts.

Last but not least, the neglect of ME/CFS has led to the non-existence of any effective treatment approaches to date. Since at the same time spontaneous remissions – as with other severe diseases – are very rare, this means for those affected that they have to expect decades of suffering until their death. This lack of perspective and secondary distress are both reasons for a high suicide rate among ME/CFS patients.

While the pathomechanism of ME/CFS is still under investigation, a causal relationship with viral infections can be established for the majority of cases. The issue of ME/CFS is therefore now experiencing even greater significance due to the current corona pandemic, since scientists worldwide believe that ME/CFS is one of the long-term consequences of Covid-19. As a result, there could soon be 100,000 additional cases in Germany alone.

We are aware that a problem as complex as ME/CFS cannot be solved by isolated measures. For this reason, it is also a particular wish of ours that the German Bundestag should take on our hopeless situation in the long term and institutionalize its commitment.

**Every single signature helps us draw attention to the currently hopeless fate of ME/CFS sufferers and their relatives. We need your help!**

For further information please visit: [www.SIGNforMECFS.com](http://www.SIGNforMECFS.com)