

## **Application**

the parliamentary group of the CDU/CSU

### **Helping ME/CFS Sufferers and Their Families – For a Better One Health and therapy care, education and recognition**

The Bundestag wants to decide:

I. The German Bundestag states:

The fact that the situation of people affected by post-infectious myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) has not improved for decades - on the contrary: the care situation of the people affected and their relatives is dramatic, characterized by hopelessness and lack of prospects and the Structures of the German healthcare system not worthy in the overall view. The fate of many people is simply overlooked.

ME/CFS is a serious multisystem disease, suspected to be of neuroimmunologic origin, leading to pathological exhaustion (fatigue) and worsening of symptoms after any exertion (post-exertional malaise). The number of people affected worldwide is estimated at around 17 to 24 million people.

ME/CFS severely restricts the quality of life of those affected: the patients are often dependent on care from relatives. Over 60 percent are unable to work, around 25 percent are unable to leave the house due to illness or are even bedridden. Some of the children and young people are only partially or not at all able to go to school, which can result in a high degree of social isolation (<https://www.mecfs.de/was-ist-me-cfs/>). Although the World Health Organization (WHO) classified ME/CFS as a neurological disease in the ICD in 1969, there is still no approved curative treatment or cure.

Even before the COVID-19 pandemic, at least a quarter of a million people in Germany were affected; including around 40,000 children and young people. It is estimated that around 1 to 2 percent of all SARS-CoV-2 infected people (up to 20 percent of all post-COVID sufferers) will meet ME/CFS diagnostic criteria after six months. It must therefore be assumed that the number of people affected by ME/CFS will almost double worldwide. In figures, this would correspond to 10 million new cases. In Germany, up to 300,000 more cases would be added, with this dimension putting a considerable strain on the health and social systems in the Federal Republic of Germany in the long term (<https://www.ardal pha.de/wissen/gesundheit/opathien/corona-post-long- covid-late effects-chronic fatigue-me-cfs-stress-syndrome-pots-100.html>). Even before the pandemic, the economic damage was estimated at over 7 billion euros a year. The damage in the EU can be estimated at around 40 billion euros per year

(<https://www.mecfs.de/wp-content/uploads/2020/09/092020-MECFS-Schaden-fu%CC%88r-die-dt.-Volkswirtschaft.pdf>).

In addition, the disease is neither recognized in Germany nor is it sufficiently known in the medical profession. This fact means that many sufferers regularly have to wait several years for a definitive diagnosis. Stigmatization and incorrect diagnoses or forms of treatment are very common, which in turn can lead to a worsening of the disease and high secondary psychological stress for those affected and their relatives (<https://www.tagesspiegel.de/wissen/heute-hort-uns-der-german-bundestag-immediately-to-4309915.html>). The difficult, if not almost impossible, social legal recognition by the health insurance companies, the medical services or the long-term care insurance contributes immensely to the precarious situation of those affected.

In addition, it must be noted that only a few scientific institutions deal with biomedical research into the disease and the development of possible treatment approaches. These include the Charité Fatigue Center (CFC, Universitätsmedizin Berlin) and the MRI Chronic Fatigue Center for Young People (CFC) for children and adolescents at the Children's Clinic of the Technical University of Munich, as well as smaller research units such as the Institute for Virology and Immunobiology at the University of Würzburg and at the University Hospital Erlangen (<https://www.bundestag.de/resource/blob/892756/b2a6381e62c7038914cae3781b18269b/Chronisches-Fatigue-Syndrom-ME-CFS-data.pdf>, <https://www.uni-wuerzburg.de/aktuelles/einblick/single/news/attack-on-the-power-plants-of-the-cell/>). These facilities are far from sufficient for appropriate care or adequate research into the disease in order to bring about a long-term improvement for those affected.

Against this background, it can be stated that the care structures for the many patients and their relatives are frightening and absolutely inadequate. There is an urgent need for nationwide, interdisciplinary and comprehensive care structures in order to alleviate the suffering of so many people in Germany, at least quickly, by ensuring good medical and nursing care. There is an urgent need for clinical testing and approval of drugs to treat the disease causally.

II. The German Bundestag calls on the Federal Government within the framework of the available budget funds to

1. to provide immediate financial and structural support for the establishment of the competence centers and interdisciplinary outpatient clinics for ME/CFS mentioned in the coalition agreement;
2. set up a central coordination office and task forces – for example within the framework of the patient representatives of the federal states; 3. to develop targeted funding for the development of biomedical therapy and to integrate a permanent budget into the individual plan 15 and the individual plan 30 of the federal budget in order to enable the prerequisites for high-quality and thus promising research; 4. to provide financial support for ME/CFS in future budget drafts, also beyond research, for example to set up telephone advice centers for those affected, their relatives and medical professionals; 5. to commission an immediate, broad-based information campaign within the framework of the Federal Center for Health Education (BZgA), the content of which will be developed with the participation of biomedical experts and with the participation of those affected;

6. to significantly facilitate or create access to health and social systems for people affected by ME/CFS by including ME/CFS in the catalog of § 116b Para. 1 SGB V and the Disease Management Program (DMP). becomes; Furthermore, by setting a chronic lump sum in order to improve care through the provision of appropriate services in the area of existing care, care and rehabilitation;
7. ME/CFS to be highlighted in the official communication of the Federal Ministry of Health (BMG) in future in order to improve the recognition of the disease and indirectly the position of those affected; 8. Accelerate research into the mechanisms of the disease and establish a biomarker that will sensitize physicians to ME/CFS and promote long-term awareness of the disease; 9. to actively participate, represented by the BMG, in the establishment of an intergroup working group using the example of the All-Party Parliamentary Group on ME in the British House of Commons and to support this group with the appropriate technical expertise; 10. campaign for the expert recognition of the illness by the medical services and thus the provision of nursing services to be improved through targeted training and education offers (with the cooperation of the BZgA) in order to relieve the family members financially and psychologically;
11. to promote rehabilitation offers for relatives in order to reduce the physical and psychological stress on these people and to enable the severely ill to participate in school or work; 12. To support rehabilitation facilities in the development of disease management concepts that do justice to the respective symptom complexes and special features such as stress intolerance (post-exertional malaise – PEM) and want to offer rehabilitative therapies for mild cases; 13. Advocate for ME/CFS to be included in the curricula or catalogs of learning objectives of medical faculties in Germany in order to raise awareness of the disease and draw the attention of young medical professionals to this symptomatic picture; 14. to set up a comprehensive range of digital information by the BMG – with the offer to involve the state ministries – which deals with the symptoms, care, treatment, research and other important information on ME/CFS; the design of the content is carried out with the participation of proven experts and with the participation of those affected;
15. to coordinate all measures for the care of the post-COVID sufferers with the establishment of the long-COVID outpatient clinics, as a significant proportion of those affected develop ME/CFS.

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**Friedrich Merz, Alexander Dobrindt and faction**

