

#SIGNforMECFS | Petition 122600 to the German Bundestag:

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



Press release by the petition team, Nov. 16th 2021

## Huge success and a strong call for help to the German Bundestag: No less than 93,033 signatures for #SIGNforMECFS

The four-week signing period of our petition 122600 to the German Bundestag ("Healthcare, Scientific Research and Political Support for ME/CFS Sufferers!") ended on Nov. 9th, 2021. During this time, a total of 57,766 electronic endorsements for the causes of the petition were recorded via the parliamentary petition portal. In addition, 35,267 signatures collected on paper were sent in and counted by the Petitions Committee Secretariat (as of Nov. 16th, 2021). Thus, within only 28 days, a total of at least 93,033 people have made the decision to support our petition. This makes our petition in the field of "disease control" the most successful petition ever submitted via the petition portal of the Bundestag. Since the quorum of 50,000 signatures has been reached, there will also be a public hearing by the Petitions Committee of the German Bundestag on our matters.

ME/CFS ("Myalgic Encephalomyelitis/Chronic Fatigue Syndrome") is a severe neuroimmunological disease. The number of people affected in Germany is estimated at about 250,000, making ME/CFS there about three times more common than HIV/AIDS. ME/CFS is currently incurable and affects young people in particular. Both factors contribute to the enormous socio-economic costs of ME/CFS, which are calculated at € 40 billion annually for the EU.

ME/CFS is a neglected disease which, despite its frequency and severity, is not part of the curriculum at any German university, for example, and is therefore hardly known by the medical profession. When it comes to ME/CFS, healthcare or research structures are currently non-existent in Germany. At the same time, the broad symptom picture of ME/CFS results in two thirds of those affected being permanently unable to work, and one quarter are even unable to leave their house or bed due to their condition.

Decades of neglect of ME/CFS have particularly resulted in the fact that the approximately 250,000 severely ill patients and their relatives are still unable to get any help in most cases. *Prof. Dr. Carmen Scheibenbogen*, immunologist at the Charité Berlin, had recently described the current situation of those affected on German television ("*Markus Lanz*" on May 12th, 2021) as follows:

*"We have very, very many people who are ill [with ME/CFS] after infections, some of whom have been ill for 20 or 30 years and are just vegetating at home without any adequate care."*

In view of this devastating situation, we, as a small group of ME/CFS sufferers, have decided in autumn 2020 to approach the German Bundestag through a petition with an urgent request for help. After long preparation, the petition was submitted on April 9th, 2021 and was finally published on the parliamentary petition portal on Oct. 12th, 2021 for signing. Our project, called "#SIGNforMECFS", received support from patient organisations, physicians, scientists and celebrities from Germany and from many other countries, as well as from German federal and state politicians. Above all, however, the overwhelming commitment of many other affected people, their relatives and friends has helped our petition to succeed. Our heartfelt thanks go out to all those who have signed, promoted or otherwise supported our petition!

*Sonja Kohl*

*Daniel Loy*

*Claudia Schreiner*

*Kevin Thonhofer*

For more information, please visit our website: [www.SIGNforMECFS.com](http://www.SIGNforMECFS.com)