

Oslo, October 14th, 2019

To whom it may concern

Regarding: ME (Myalgisk encephalopathy/myelitis)

ME has for years been a controversial disease. However, in 2015 this changed when the Institute of Medicine (IOM) ¹, and subsequently Centers for Disease Control (CDC), National Institutes of Health (NIH) in USA, as well as the advisory report from the Dutch Health Council², based on analysis of more than 9.000 peer-reviewed studies, concluded that ME (also called CFS) is a serious chronic multisystem and biological disease that substantially limits the activities and quality of life of patients.

ME is a complex and physical disease for which there is currently no cure. It is clear that it is not a psychological or psychosomatic disease. There is strong scientific evidence of neurological/autonomic dysfunction, immunologic and inflammatory pathologies, microbiome perturbation, metabolic/mitochondrial as well as cardiac abnormalities in ME patients. Some of this new knowledge was recently summarized. ³

Based on this scientific evidence, there is an imminent need to avoid that patients are misdiagnosed or further stigmatised by falsely equating the disease with (chronic or unexplained) fatigue, deconditioning or psychosomatic classifications, like functional disorders, medically unexplained symptoms, somatoform disorders, somatic symptom disorder, functional somatic syndrome, neurasthenia, or bodily distress disorder/syndrome.

It is therefore concerning that the Child welfare in several countries including, my own, starts custody cases threatening to remove young ME patients from their families by police force into emergency placement in youth centers or fosterhomes for an indefinite length of time.

These child protection cases are based on the not updated view that ME is a functional disorder that can be dealt with by ignoring physical symptoms and increasing scholarly, physical and social activity. Parents are accused of life-threatening neglect by letting their children rest in isolation. This attitude ignores the WHO classification, the IOM report, CDC recommendations, biomedical research, international consensus definition of ME/CFS as a serious somatic disorder in which over-exertion may have long-lasting or even permanent detrimental effects.

To my knowledge it has never been proven any benefits from removing such patients from their parents. By the contrary, in my own country such non-evidence based practice has contributed to much harm and should not be accepted any longer.

Sincerely yours

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¹ IOM 2015 report

² <https://www.gezondheidsraad.nl/en/task-and-procedure/areas-of-activity/optimale-gezondheidszorg/mecfs>

³ Komaroff AL. Advances in Understanding the Pathophysiology of Chronic Fatigue Syndrome. JAMA. 2019 Jul 5 doi: 10.1001/jama.2019.8312