



World ME Alliance
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Dr. Tedros Ghebreyesus
Director-General
World Health Organization

Dr. Bente Mikkelsen
Director of the Division of Noncommunicable Diseases
World Health Organization

Dear Dr. Ghebreyesus and Dr. Mikkelsen,

We are so encouraged by the newly released [Global report on health equity for persons with disabilities](#). The recommendations included in the report are an important step towards addressing the needs of people with disabilities worldwide. Ensuring equitable access to all areas of society for people with disabilities is critical to the development of healthy countries and societies, and we are grateful for the recommendations provided in this report.

Despite our appreciation for the steps suggested in the current version of the report, we the undersigned 21 organizations of the World ME Alliance feel that persons with chronic illnesses, and specifically those living with energy-limiting disabilities like Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) could have received more attention, input opportunities, and guidance in the report.

Specifically, we noticed that energy-limiting disabilities, such as the impairment caused by post-exertional malaise (also known as post-exertional symptom exacerbation) were not explicitly mentioned at all in the report, though the study entitled, "What stops children with a chronic illness accessing health care: a mixed methods study in children with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME)" was referenced 7 times. We also noticed that despite the acknowledgment on page 26 that, "1 in 5 people will have a new disability when assessed six months after COVID-19 hospitalization," there was little acknowledgment of the unique complexity of navigating the energy-limiting forms of disability experienced by those with infection associated illnesses like ME/CFS. Nor was there recognition of the distinct stigma facing this group. Furthermore, this acknowledgement should be widened beyond those



hospitalized by COVID-19, as many people have long lasting effects that begin after a mild infection. Our concern is that without being expressly described in the report, those with ME/CFS, long COVID, and other energy-limiting disabilities will be left behind or excluded from achieving the health equity that recommendations in this report intend to create.

We, the undersigned, have several recommendations to more fully integrate those with energy-limiting disabilities such as ME/CFS and long COVID into the upcoming “Guide for Action” being developed to support countries to implement the recommendations:

1. We recommend the creation of a committee or working group for the WHO for those disabled by energy-limiting illnesses - thus creating a mechanism for securing input from that community in the future.
2. We suggest a section in the “Guide for Action” describing energy-limiting disabilities, and including a definition of post-exertional malaise. We believe it would be beneficial to include a story from someone with an energy-limiting disability in this toolkit.
3. We noticed that the report mentioned on page 26 that the “evidence on how COVID-19 impacts disability prevalence in populations is still evolving,” and would instead contend that there has been a large amount of research clearly demonstrating the disabling impacts of COVID-19. We recommend an update to this section, or a section defining post-viral illness, in the upcoming “Guide for Action.” This would create an acknowledgement of research advances which have been made both in defining the scope of the disabling and long-term effects that people experience post-COVID, and in assessing the breadth of the impact societally.

We are eager to meet with you and other designated WHO representatives to improve the equitable inclusion of these communities in the future. We hope that this letter can be the first step towards future conversations and collaborations together.

Our aim is equitable representation and meaningful improvement to the quality of life of people disabled by these invisible and energy-limiting factors.

Respectfully,

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Co-chair, World ME Alliance
CEO, Solve M.E.



Sian Leary
Head of Advocacy and Communications, World ME Alliance

Signatories:

- #MEAction (International)
- 12ME (Belgium)
- ACAF - Associació Catalana d'Afectades i Afectats de Fibromiàlgia i d'altres Síndromes de Sensibilització Central (Spain)
- Action for M.E. (United Kingdom)
- AMMES - The American ME and CFS Society
- ANZMES – The Associated New Zealand Myalgic Encephalomyelitis Society
- AQEM – Association québécoise de l'encéphalomyélite myalgique (Canada)
- CFS/ME Associazione Italiana (Italy)
- European ME Coalition
- Forward M.E. (United Kingdom)
- Hope 4 ME & Fibro Northern Ireland
- Japan ME Association
- ME Support (IOM) (Isle of Man)
- ME/ CVS Stichting Nederland (Netherlands)
- Millions Missing Belgique (Belgium)
- Millions Missing Canada
- Millions Missing France
- Plataforma Familiars FM-SFC-SQM Síndromes de Sensibilització Central (Spain)
- Solve M.E. (United States)
- The ME CFS Foundation South Africa
- WAMES – Welsh Association of ME & CFS Support (Wales)

