

Dear Dr Ghebreyesus,

Our World ME Alliance read your recent [Guardian article](#) “The data is clear: long Covid is devastating people’s lives and livelihoods” with great interest.

We would like to congratulate you and the World Health Organization for taking this issue so seriously. In particular, we appreciate your acknowledgement of the devastation Long Covid is causing, the need to listen to patient groups, and the need for sustained investment to expand our scientific understanding so better treatments and clinical management can be developed.

While we congratulate the efforts to innovate around Long Covid, we also see that people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), many of whom have already suffered decades of the same devastation you have described, face a lack of recognition and global response.

The most prevalent Long Covid symptoms — crippling fatigue, post-exertional malaise, widespread inflammation, and cognitive dysfunction — mirror those of ME/CFS. As more research is undertaken, it is becoming clearer that a large proportion of those with Long Covid now meet the criteria for an ME/CFS diagnosis, also known to be a viral-associated disease. Additionally, many studies^{1, 2, 3, 4, 5} are making key scientific connections between ME/CFS and Long Covid.

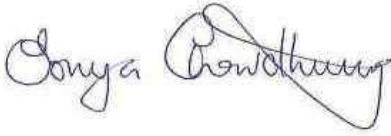
This is not new. Outbreaks of viruses such as swine flu (H1N1) and Ebola, as well as common viruses including Epstein-Barr Virus (EBV), demonstrate that chronic illness triggered by viral infections, including ME/CFS, are a recurrent phenomenon.

We would welcome a meeting with you to follow up on [past commitments](#) to establish contact with ME/CFS experts and patient organisations. We believe this could fast track support for people with ME/CFS and also those with Long Covid, ensuring learnings from ME/CFS are taken advantage of, and that progress for people with Long Covid doesn’t leave those with ME/CFS behind.



Yours sincerely,

Sonya Chowdury, Co-Chair of the World ME Alliance, CEO of Action for M.E.



Oved Amitay, Co-Chair of the World ME Alliance, President and CEO of Solve M.E.



Sian Leary, Head of Advocacy and Communications, World ME Alliance



World Alliance

- #MEAction
- 12ME
- ACAF – Associació Catalana d’Afectades i Afectats de Fibromiàlgia i d’altres Síndromes de Sensibilització Central
- Action for M.E.
- AMMES – The American ME and CFS Society
- ANZMES – The Associated New Zealand Myalgic Encephalomyelitis Society
- AQEM
- CFS/ME Associazione Italiana
- European ME Coalition
- Forward M.E.
- Hope 4 ME & Fibro Northern Ireland
- ME Support IOM
- ME/ CVS Stichting Nederland
- Millions Missing Canada
- Millions Missing Belgique
- Plataforma Familiars FM-SFC-SQM Síndromes de Sensibilització Central
- Solve M.E.
- The ME CFS Foundation South Africa
- WAMES – Welsh Association of ME & CFS Support



Endnotes

1. Davis, Hannah E., Gina S. Assaf, Lisa McCorkell, Hannah Wei, Ryan J. Low, Yochai Re'em, Signe Redfield, Jared P. Austin, and Athena Akrami. "Characterizing long COVID in an international cohort: 7 months of symptoms and their impact." *EClinicalMedicine* 38 (2021): 101019.
[https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370\(21\)00299-6/fulltext](https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext)
"Found the most frequent symptoms after month 6 were fatigue, post-exertional malaise, and cognitive dysfunction. Symptoms varied in their prevalence over time, and we identified three symptom clusters, each with a characteristic temporal profile."
2. Mancini, Donna M., Danielle L. Brunjes, Anuradha Lala, Maria Giovanna Trivieri, Johanna P. Contreras, and Benjamin H. Natelson. "Use of cardiopulmonary stress testing for patients with unexplained dyspnea post-coronavirus disease." *Heart Failure* 9, no. 12 (2021): 927-937.
<https://pubmed.ncbi.nlm.nih.gov/34857177/>
"This is the first report to indicate a high rate of patients with PASC meeting criteria for ME/CFS (46%), which is consistent with what was found after the SARS COVID-1 outbreak."
3. Wong, Timothy L., and Danielle J. Weitzer. "Long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)—a systemic review and comparison of clinical presentation and symptomatology." *Medicina* 57, no. 5 (2021): 418.
<https://www.mdpi.com/1648-9144/57/5/418/htm>
"All three major criteria symptoms as specified by most ME/CFS case definitions... were reported by multiple selected long COVID studies, with fatigue being the most reported symptom.... All sub-categories within the minor criteria of ME/CFS... were matched with long-COVID studies."
4. Paul, Bindu D., Marian D. Lemle, Anthony L. Komaroff, and Solomon H. Snyder. "Redox imbalance links COVID-19 and myalgic encephalomyelitis/chronic fatigue syndrome." *Proceedings of the National Academy of Sciences* 118, no. 34 (2021): e2024358118.
<https://www.pnas.org/doi/10.1073/pnas.2024358118>
"People with acute COVID-19 and people with ME/CFS share redox imbalance, systemic inflammation and neuroinflammation, impaired production of ATP and other abnormalities in common, abnormalities that have bidirectional connections."
5. Klein, Jon, Jamie Wood, Jillian Jaycox, Peiwen Lu, Rahul M. Dhodapkar, Jeffrey R. Gehlhausen, Alexandra Tabachnikova et al. "Distinguishing features of Long COVID identified through immune profiling." *medRxiv* (2022).
<https://www.medrxiv.org/content/10.1101/2022.08.09.22278592v1>
"Analysis of circulating immune mediators and various hormones also revealed pronounced differences, with levels of cortisol being uniformly lower among participants with Long COVID relative to matched control groups. Integration of immune phenotyping data into unbiased machine learning models identified significant distinguishing features critical in accurate classification of Long COVID, with decreased levels of cortisol being the most significant individual predictor."

