Dr Tedros Adhanom Ghebreyesus
World Health Organisation
Avenue Appia 20
1202 Geneva

11 May 2018

CC Dr Svetlana Akselrod,
Assistant Director General for Non-Communicable Diseases and Mental Health

Dear Dr Tedros

Urgent action to address M.E. globally: a neglected NCD

Tomorrow, on 12th May, people across the globe will come together in public spaces, at government buildings, online and in their homes to ask: “Can you see M.E. now?” You can see their films, photographs and stories, shared for this global M.E. Awareness Day event, at www.facebook.com/MEActNet and www.twitter.com/IAforME

M.E. (Myalgic Encephalomyelitis) is a complex, disabling, chronic, fluctuating, neurological condition of unknown aetiology. It is sometimes diagnosed as Chronic Fatigue Syndrome or CFS/M.E. It is a disease which affects 20,000,000 individuals of all ages and from all ethnic groups – and the families around them – causing significant personal, social and economic hardship.

The US government’s landmark report, *Beyond M.E./CFS: redefining an illness*, made it clear that M.E. is “a serious, chronic, complex, and systemic disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those whom it afflicts.”[1]

M.E. is associated with neurological, immunological and energy-metabolism impairment, and is characterised by significant disability and a widespread intolerance to even small amounts of mental and physical exertion. Other symptoms include sleep dysfunction, dizziness, widespread pain, cognitive dysfunction, and sensitivity to light and sound. We know that:

- one in four people with M.E. are so severely affected that they are unable to leave their beds or homes, sometimes for many years, too ill to bear even the touch of a loved one
- M.E. has the lowest health-related quality-of-life score when compared to cancer, diabetes, lupus, stroke, heart disease and chronic renal failure[2]
- people with M.E. are at an increased risk of cancer, heart disease, and suicide[3]

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[1] Institute of Medicine (2015) *Beyond M.E./CFS: redefining an illness* www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx

[2] Hvidberg et al (2015) The Health-Related Quality of Life for Patients with ME/CFS. *PLoS ONE*

[3] Dimmock at al (2016) Estimating the disease burden of ME/CFS in the United States and its relation to research funding. *Journal of Medicine and Therapeutics*

- in children and young people, the disease is the most common cause of long-term school absence.[4]

Despite this suffering and disability, and the urgent need to find effective treatments, only 0.02% of international mainstream research funding has been directed towards M.E.[5] Moreover, the condition is frequently undiagnosed, misdiagnosed and/or mistreated by physicians and often not recognised by national treatment and health insurance systems.

The International Alliance for M.E.'s awareness event on 12th May in Geneva, just one of thousands of Millions Missing[6] events across the world, is part of our work to highlight the challenges faced by people with M.E.

We would greatly appreciate it if you could make time in your busy schedule to meet representatives from the International Alliance for M.E., a new collaboration uniting M.E. organisations in the US, Australia, Spain, Japan, South Africa and the UK. We would like to highlight the serious and significant impact of this often unrecognised condition, and explain why we are seeking urgent national and international action to increase research on the condition and ease the suffering of patients around the world.

We hope that, with the support of Members States and WHO, we will:

1. Recognise M.E. as a "serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients"[7] and adopt measures to provide a global and co-ordinated public health response to it.
2. Put in place transparency and a consultation process with M.E. organisations and patients on decisions related to M.E.
3. Support accelerated biomedical research to develop better diagnostic methods and treatments for M.E.
4. Ensure appropriate medical education for professionals working with M.E. patients.

As advocates, organisations, patients and carers, the International Alliance for M.E. is determined to see the condition properly recognised and treated, working with scientists and researchers across the world. We very much hope for your support for people living with M.E.

In the hope of your favorable reply to our invitation to meet,

Yours sincerely

The International Alliance for M.E.

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[4] Dowsett and Colby (1997) Long-term sickness absence due to ME/CFS in UK schools; an epidemiological study with medical and educational implications. *Journal of Chronic Fatigue Syndrome*

[5] Chowdhury and Radford (2016) *M.E./CFS research funding* www.actionforme.org.uk/uploads/pdfs/mecfs-research-funding-report-2016.pdf

[6] https://millionsmissing.meaction.net

[7] Institute of Medicine (2015) *Beyond M.E./CFS: redefining an illness* www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx

ACAF - Associació Catalana d'Afectades i Afectats de Fibromiàlgia i d'altres Síndromes de Sensibilització Central, Spain
Action for M.E., United Kingdom
The American ME and CFS Society, United States
Emerge Australia, Australia
Forward ME, United Kingdom
Japan ME Association, Japan
ME CFS Foundation South Africa, South Africa
Plataforma Familiars Fm-SFC-SQM, Spain
Solve ME/CFS Initiative, United States

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#MEAction, United Kingdom
ME/CFS Association Switzerland / Verein ME/CFS Schweiz, Switzerland
ME/FM Society of BC, Canada
ME Research UK, United Kingdom
Millions Missing Canada, Canada
Millions Missing France, France
National ME/FM Action Network, Canada
Open Medicine Foundation, United States
Welsh Association of ME & CFS Support (WAMES), United Kingdom