

Inspiring action at all levels:

International advocacy for M.E.

Through a coordinated, inclusive and worldwide advocacy movement along with the current mobilisation of the M.E community, the aim of international advocacy is a coordinated and appropriate public health response to M.E. led by the World Health Organisation (WHO) and its Member States.

Being developed as part of Action for M.E.'s wider policy programme, our international advocacy work will achieve this aim through the following objectives:

1. Facilitating an international advocacy movement targeting the WHO and its Member States
2. Getting M.E. on the international policy agenda by raising awareness at the highest political level, the United Nations
3. Developing and initiating an international public health policy for M.E. by leveraging political leadership from the WHO and its Member States through the adoption of a World Health Assembly (WHA) resolution.

Why international advocacy?

“International advocacy” refers to influencing and advocating at the highest decision-making level with those who hold authority and accountability on, and for, health-related matters. The level of change needed requires a ‘top-down’ approach which will mandate action alongside the ‘bottom up’ or grassroots approach that is taking place currently.

This ‘high level’ decision-making takes place through the WHO and its various decision-making fora including the WHA, the WHO’s supreme decision-making body.

“The World Health Assembly is the decision-making body of WHO. It is attended by delegations from all WHO Member States and focuses on a specific health agenda prepared by the Executive Board. The main functions of the World Health Assembly are to determine the policies of the Organization, appoint the Director-General, supervise financial policies, and review and approve the proposed programme budget. The Health Assembly is held annually in Geneva, Switzerland.” [World Health Organisation website; 23.9.15]

Securing a commitment to action (resolution) on M.E. by the WHA will require Member States of the WHO to deliver on its commitment and to report back on progress. They are mandated to do this and there are consequences of not complying, therefore engagement at WHO level has the potential to directly influence work at a national level in relation to policy and setting the health agenda.

An International Advocacy Strategy (see Appendix 2) will lead to increased success/return on investment at national level for people with M.E. and for the respective charities/organisations in the following ways:

- Increased access to top national government officials – in preparation for, and at, WHA
- National governments' commitment to M.E. through WHA resolution (which can only be secured through international action)
- Increased global awareness of the disease (at WHO and across other countries)
- Enhancing a coordinated public health debate lead by the WHO
- Opportunity to find and adopt best practices across national boundaries
- Improved access to research and science taking place in other countries
- Increased stature of M.E organisations with stakeholders and funders
- Increased funding.

What will this work achieve?

This programme of work was commissioned by Action for M.E. (see Appendix 1) with the goal of setting up a coordinated movement, in partnership with every relevant stakeholder.

Working with the International Alliance for M.E. and the global M.E. community (see page 3), this work aims to raise awareness about M.E. and mobilise the international public health community at WHO policy level to respond to the urgent public health needs of people affected by M.E.

We want the WHO to provide leadership and to engage with relevant stakeholders, including patients, in a constructive dialogue to ensure inclusive responses and adoption by the WHO Member States of appropriate public health measures.

In particular, we want the WHO and its Member States, through the adoption of a resolution at the WHA, to:

- 1. Recognise M.E. as a “serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients” (Institute of Medicine, 2015) 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.**

For an example of WHA resolutions on specific diseases, see the WHO's [resolution on Mycetoma](#) and [resolution on Epilepsy](#).

How do we want to achieve our objectives?

a) The synergy: a global joint advocacy movement

International advocacy for M.E. complements and integrates with existing advocacy work at national and regional level led by national and regional M.E. organisations, with the researchers community progress and above all, with the M.E. community mobilisation worldwide.

This is not an isolated project sitting on its own: international advocacy activities will benefit national and/or regional advocacy work and vice versa. It is only if this synergy can be achieved that we will realise the overall aim, which is to address the M.E. community's needs at an international level in order to see a coordinated and high level response from the WHO.

b) The critically important involvement of the International Alliance for ME (IAME)

A collaboration between M.E. organisations across the world, the IAME was initially conceived to offer a formal consultation channel to WHO, as an alternative to the fragmented lobbying that we have seen within the wider M.E. community.

The coordination of M.E. organisations' international advocacy through the IAME will facilitate:

- a coordinated and simultaneous dialogue with policy makers at national and international levels, which will increase our potential impact;
- the pooling, sharing and dissemination of advocacy and communication resources (sharing information; social-media tools such as twitter, Facebook);
- the expansion of engagement with relevant stakeholders: worldwide organisations sharing the same message is much more powerful than isolated voices particularly when we want the Member States of the WHO to act together.

To contribute to the joint global advocacy movement and to achieve our goal, IAME will work through regular videoconference calls with an agreed agenda and minutes. Action for M.E.'s Head of International Advocacy for M.E. (see Appendix 1) will facilitate the IAME coordination and implement agreed actions.

c) The essential role of the M.E. community

The current mobilisation of the global M.E. community, notably through Millions Missing and/or #MEAction, represents unique momentum through which to potentially leverage political leadership at international policy level. The voices, experiences and involvement of patients are essential. Policy makers and the WHO are accountable to patients.

To this end a Call for Action to the WHO and its Member States would be a powerful advocacy tool used simultaneously at national, regional and international levels.

Implementing international advocacy

In order to allow us to achieve our objectives, we are aiming for a three to four year timeline, depending on the outcome of each milestone. Our international advocacy work will be implemented according to two main phases:

Phase one: Setting-up, building awareness at global policy level and securing initial commitments from key policy makers and partners

- a) Reaching out to M.E. organisations and relevant partners to tell them about the work and invite collaboration
- b) Facilitating IAME coordination and joint actions
- c) Building awareness and engaging in a constructive dialogue about M.E. with identified stakeholders at international level (eg. WHO, Member States' Geneva representatives) notably a first event during the WHA in May 2018 where will be screened a 20 minutes version of the movie Unrest followed by a debate with policy makers and other stakeholders
- d) Facilitating a Call for Action to WHO and Member States from the M.E. community.

Phase Two: Towards political leadership through the adoption of a resolution on M.E. by the World Health Assembly

- a) Getting at least two Member States Champions to drive this at international level and carry the resolution to the WHO
- b) Building-up Member States coalition to support the resolution
- c) Strong advocacy and communications mobilisation to get the adoption of the resolution by the WHA.

Appendix 1: Alexandra's role and background

Action for M.E. has commissioned this international advocacy work through the Union for International Cancer Control (UICC), a formal partner of World Health Organisation (WHO). To achieve our ambitious goals, Alexandra Heumber, based in Geneva, has, in effect, been seconded to lead this piece of work as Action for M.E.'s Head of International Advocacy ([the public announcement can be read here](#)), notably by coordinating the IAME for joint actions when appropriate.

Alexandra's background:

- 15 years of public affairs experience at international and European level, specialised in public health and pharmaceutical issues, working in NGOs, such as Médecins Sans Frontières, public development partnerships on neglected diseases, government and pharmaceutical industry;
- Solid expertise in United Nations and European Union institutional relations, high level diplomacy, policy and advocacy, i.e. leading the policy and advocacy for the adoption of the Mycetoma WHA resolution, for the resolution on Access to Medicines at WHA and resolution at European Parliament, setting-up of the European Parliament Group on Access to medicines);
- Substantial understanding of the issues surrounding access to treatment, human rights, R&D and pharmaceutical policy;
- Track record in initiating, coordinating and managing projects with cross-cultural and multidisciplinary teams.

Appendix 2: International advocacy: our strategy



