



World **ME** Alliance

ANNUAL REPORT

1ST APRIL 2022 - 31ST MARCH 2023

TO A WORLD WITHOUT ME

CELEBRATING GROWTH, COLLABORATION, AND IMPACT

As Co-Chairs of the World ME Alliance, we are delighted to present this annual report, reflecting on the progress we have made in advancing global collaboration around Myalgic Encephalomyelitis (ME) advocacy. This year has been marked by significant growth that has strengthened our collective voice and expanded our reach.

For the first time we are seeing interest and engagement from officials at the World Health Organization (WHO), that we aim to convert to concrete actions.

We are proud that our Alliance has spoken out on crucial issues, challenging misconceptions, and demanding change.

And we celebrate our increase from 13 to 21 member organisations.

As we reflect on our achievements, we recognise that our journey continues. The challenges faced by ME patients persist, and our work is far from over. However, with a growing membership, strong global collaborations, bold advocacy efforts, and a dedicated team, we are confident in our ability to make a lasting impact.

We extend our deepest gratitude to our members, partners, supporters, and the ME community for their unwavering commitment. Let us move forward with renewed determination, knowing that our collective efforts can bring about real change and a brighter future for all those affected by ME.

Sonya Chowdhury and Oved Amitay
- Co-chairs of the World ME Alliance



OUR AIM:

AN APPROPRIATE PUBLIC HEALTH RESPONSE FROM THE WORLD HEALTH ORGANIZATION AND ITS MEMBER STATES, AS OUTLINED IN THE WORLD ME ALLIANCE MEMORANDUM OF UNDERSTANDING

IMPACT

Global recognition of ME and commensurate funding of services, research and charities

OUTCOMES

A global alliance of ME organisations able to speak with one voice

Established communication channels with WHO departments and member states

Increased awareness of ME, and ability and credibility of ME organisations

ACTIVITIES

- Membership building
- Sharing knowledge and experience through meetings and other channels
- Establishing agreed positions on matters of importance

- Participating in WHO activities
- Reaching of the WHO officials both directly and through our members
- Responding to WHO publications

- Growing World ME Day and cooperatively unifying around themes
- Speaking out together
- Providing reciprocal support and advice between member organisations
- A global presence on social media

INPUTS

Staff time; member's time; volunteer's time; website hosting & IT licenses



MEMBERSHIP

Through 2022 we brought on board eight new member organisations, including our first member organisation in Asia.

We are thrilled to report that the membership of the World ME Alliance has grown significantly over the past year. We have successfully expanded our network from 13 to 21 organisations, now representing 17 countries worldwide. This growth is a testament to the increasing recognition and importance of our collective efforts in addressing the challenges faced by individuals living with ME.

One of the notable milestones in our membership expansion is the inclusion of our first member organisation from Asia. This development marks significant steps forward in our mission to foster global collaboration and address the needs of ME patients in diverse regions. The inclusion of our new members has enriched our perspective, allowing us to gain insights into the unique challenges faced by individuals living with ME across the world, and begin to tailor our advocacy and support initiatives accordingly.

Our new members:

- [Hope 4 ME & Fibro Northern Ireland](#)
- [European ME Coalition](#)
- [Millions Missing Canada](#)
- [ME CVS Nederland](#)
- [ME Support \(IOM\)](#)
- [Millions Missing Belgique](#)
- [Millions Missing France](#)
- [Japan ME Association](#)



MILLIONS MISSING CANADA



EMEC
EUROPEAN ME COALITION

mecvs Nederland



ACTIVITIES

Collaboration. Cooperation. Coordination.

We held meetings roughly every 6 weeks, engaging by email with those who were unable to attend. Minutes, presentations and papers from meetings were made available to all to comment on.

By the end of the year we had 36 advocates from our member organisations engaging via email, with most attending some meetings through the year.

We also held meetings of our subgroups, developed terms of reference for these, and encouraged active participation from our members.

Through our meetings our members were able to share the challenges of ME advocacy, calling for advice from other organisational leaders, and celebrating successes from new research to government engagement.

As part of our efforts to reach out, we opened a new LinkedIn page, choosing this platform as it is well used by professionals within the WHO.

This report goes on to detail our work on key activities such as engaging the WHO, our flagship event World ME Day, the development of subgroups and more.

"Through collaborative action, we are building a stronger voice for people with ME everywhere."

- Sian Leary, Head of Advocacy and Communications



World Day

On May 12th 2022 we launched the inaugural World ME day, bringing together organisations and individuals to advocate on a common theme: #LearnFromME.

The new World ME Day initiative brought together organisations and unified efforts to raise awareness and campaign together on Myalgic Encephalomyelitis (ME).

This campaigning day follows in the footsteps of other successful initiatives such as [World Cancer Day](#) and [World MS Day](#). By focusing on one specific day, and sharing materials, logos and content, these campaigns have grown to have a major impact. World ME Day aims to demonstrate the incredible global collaboration and unity that the ME community can achieve.

The World ME Alliance launched it's own series of resources, publicly available for anyone in the world to use. These included information on the 2022 theme #LearnFromME, a custom-poster maker, [a campaign film](#), actions for individuals to take, research alerts and round-ups of everything taking place globally.

During this inaugural year, we succeeded at launching the World ME Day name and brand, achieving broad engagement and positive reactions. However, we still face challenges in converting some groups and individuals from using previous hashtags and names for this day, that we hope to improve upon in future years.

Our members undertook varied actions from interviewing professionals, lighting over one hundred buildings in blue, working with government health officials to release statements, collaborating with press on articles, holding photo contests, and launching short film series.

I learnt that...

After my life became smaller and less active, it was still full of love and depth, and I have strength I didn't know I had

Will you #LearnFromME?

World  Day



OUR TEAMS

Establishing working groups and bringing onboard a volunteer

This year saw the establishment of multiple working groups within the World ME Alliance.

Our first group focussed on World ME Day, with a few member organisations volunteering individuals to support the development of this inaugural campaign.

Our second group, titled the WHO Strategy Subgroup, was established with a primary focus of working to achieve our key goal: "a formal consultation channel with the WHO to represent the millions of people affected by ME and bring forth greater technical input into the design and delivery of health and other services to respond to their needs."

In July, the Alliance members approved a new role of co-chair to spread workload and ensure representation. Oved Amitay, CEO of Solve M.E. was subsequently approved as our new co-chair for the first term of this role.

Finally, this year saw the first Communications Volunteer join the World ME Alliance. Their remit is predominantly focused on supporting the growth of the World ME Alliance's social media, including our new LinkedIn page. With management and support from the Head of Advocacy and Communications, this volunteer is now writing posts for our social accounts each week, and hopes to grow to support a greater variety of actions.



ENGAGING THE WHO

Establishing the World Health Organization (WHO) Strategy Subgroup and connecting with WHO officials.

Following the establishment of the WHO Strategy Subgroup, we created our terms of reference and agreed upon a fluctuating membership model to enable as much participation as possible. This group has since carefully considered strategy, deliberating on how best to engage with the WHO. Through the year, we have reached out to other associated disease organisations on a fact-finding and relationship building mission.

We have also directly targeted the WHO, writing open letters in response to WHO activities and statements, and holding meetings with WHO officials.

We held our first meeting with four officials from the WHO Disability Team and WHO Brain Health Unit in January 2023, following outreach in relation to the publication of their "Global report on health equity for persons with disabilities". This has led to ongoing engagement with the Disability Team.

Member organisations have begun to use their connections

within governments and beyond to build contact with national missions.

From an introduction via the Japan ME Association we met with the WHO Director of Health Promotion.

Via Action for M.E. we called for advice from Union for International Cancer Control (UICC) advocates with significant experience working with the WHO. Via ME CVS Nederland we established first contact with the Netherlands WHO National Counterpart. And via the ME CFS Foundation South Africa we met with the co-chair of the Intergovernmental Negotiating Body to draft and negotiate a WHO convention, agreement or other international instrument on pandemic prevention, preparedness and response (INB).

The strategy group will continue in their efforts to engage these individuals and associated disease organisations, building greater awareness of ME within the World Health Organization and focusing on garnering concrete action.



SPEAKING OUT

Speaking as a global Alliance on the issues that matter

Through our membership we are beginning to identify key issues that can benefit from global statements.

This year saw a rise in the promotion of the commercial programme named the Lightning Process as a treatment or cure for ME in some countries, without due evidence.

In response, we developed a position paper based on the best available evidence. The paper states "The World ME Alliance and its members do not endorse the Lightning Process for people with Myalgic Encephalomyelitis (ME), sometimes called Chronic Fatigue Syndrome (CFS)."

Oved Amitay, co-chair of the World ME Alliance and CEO of Solve M.E., spoke out about this statement:

"We're taking this unusual position because of the unusual circumstances. What we recommend here is really based on our philosophy that what our community deserves is well-researched, evidence based treatments."

By speaking with a unified voice on this issue, our Alliance provided backing for members to challenge the misinformation and grandiose claims being made that could lead to the harm of people with ME.



VISION FOR THE FUTURE

A world without ME

Our Alliance has its sights set on a bold and ambitious vision for the future. As we continue to grow our global membership, strengthen our relationships and connections with the World Health Organization (WHO), and celebrate the success of our flagship event, World ME Day, we are determined to make a lasting impact in the field of ME advocacy and support. Together, we envision a future where ME patients receive the recognition, resources, and care they deserve, and where our alliance becomes a global catalyst for change.

Our vision extends beyond awareness to

tangible improvements in the lives of ME patients. We will continue to advocate for increased funding, research, and resources dedicated to ME. By working with governments, policymakers, and key stakeholders, we will strive to influence policies and drive investments that address the needs of ME patients and lead to breakthroughs in diagnosis, treatment, and support.

By fostering international collaboration, we are committed to making a lasting difference for ME patients and their communities.





World Alliance



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