MEAction UK Annual Report

November 2024 - October 2025

Overview

MEAction UK is a UK charity and our work centres around empowering/enabling people with myalgic encephalomyelitis (ME) and other complex, chronic illnesses (including post infectious illnesses). We carry out activities that improve the understanding of ME and help to relieve sickness through better treatment and public understanding. We are a volunteer-led group run by people with ME, families and allies. #MEAction UK leads our campaigning in England and Wales. #MEAction Scotland focusses on campaigning and advocacy in Scotland.

Parliamentary Campaigning

We concentrated our Parliamentary work in Scotland this year as, despite committing to do so in 2022, the Scottish Government had not implemented the NICE guideline until May 2025 when the Minister for Public Health and Women's Health announced that the NICE guideline should be recognised as the default guideline for Scotland.

Due to #MEAction Scotland's campaigning, ME was mentioned in the Scottish Budget for 2025-2026 for the first time, with £4.5m annual recurring funding allocated to health boards to develop services for people with Long Covid, ME and similar conditions

#MEAction Scotland volunteers met Jenni Minto, Minister for Public Health and Women's Health, along with staff from the Scottish Government's Clinical Priorities team in April 2025 (see photo below). The aim of the meeting was to discuss the implementation of the NICE guideline, the criteria for the £4.5 million budget allocation and the urgent need for training of healthcare professionals.

We also contributed to several consultations to ensure that the voice of people with ME was heard by relevant organisations. We engage with consultations either because we are invited to contribute or because they are relevant to specific campaigns. :

- Scottish Human Rights Commission: Economic, Social and Cultural Rights in the Highlands & Islands Nov 2024
- Palliative Care Matters Consultation (with Neurological Alliance of Scotland) Dec 2024
- Scottish Government's Long Term Conditions Framework June 2025

We enlisted the support of Members of the Scottish Parliament (MSPs) to chase Health Boards about gaps in data in the Scottish Government 2022 survey of ME services in Scotland, and as a result the Government reran the survey and published an updated report in November 2024 which gave a full picture of the lack of services for people with ME and the key issues faced by health boards in providing these services.

In November 2024 we held a successful Information Stand in the Scottish Parliament, engaging with 63 MSPs over 3 days. As a a results of discussions at the stall #MEAction Scotland and ME were mentioned in the Parliamentary debate on the Women's Health Plan by two MSPs.

A successful Parliamentary Question campaign resulted in 22 PQs asked about ME by nine different MSPs.

Our main campaign in the latter half of the year was focussed on raising awareness of ME in the Scottish election in May 2026, with the specific aim of getting ME mentioned in party manifestos. In April 2025, We contacted all the major parties; used our MSP champions to arrange meetings with policy staff; and provided briefings and information on request. As part of the campaign we took stalls at the Scottish Liberal Democrats and SNP Party conferences in October 2025, with plans to attend other party conferences in spring 2026. In order to increase our visibility at conferences we developed a 'Spin the Wheel' game (see photo at Lib Dem conference below) where delegates spun the wheel and selected a card with a fact about ME according to which segment they landed on. The use of an interactive game meant that we attracted delegates' attention and was a very effective way of engaging with them, providing the opportunity to discuss the key issues faced by people with ME.

#MEAction UK asked Wes Streeting and Andrew Gwynne MP if they would commit to challenge and change the neglect of people with ME and push the Department of Health and Social Care (DHSC) to publish a plan that contains more than warm wishes and good intentions and the National Institute for Health and Care Research to commit significant research funds.

Sadly, in February 2025, in a statement to parliament, Ashley Dalton's, minister for public health, and replacement for Andrew Gwynne MP, response made clear that: "There are currently no plans to allocate additional funding towards the myalgic encephalomyelitis/chronic fatigue final delivery plan." This is a blow for all those with ME, especially the severely and very severely affected. It is an unacceptable outcome to a process that started in August 2023, and which has demanded a great deal of input from the ME community who now feel abandoned. We are committed to campaigning until the government and research funders commit to funding ME research in parity with other diseases.

In July 2025 we published our response to the DHSC's ME/CFS Delivery Plan. MEAction UK remains disappointed by its content with minimal sums of money committed to ME research. £1.4 million and a competitive award do not replace the millions of pounds missing from ME research and care.

For full details see of our response to the Delivery Plan see #MEAction UK's response to the DHSC Delivery Plan and #MEAction Scotland's response to the DHSC Delivery Plan

#MillionsMissing

#MEAction UK

Every year, on May 12th, ME Awareness Day, we run #MillionsMissing campaign on behalf of people with ME with the goal of demanding an increase in research and care for the #MillionsMissing with myalgic encephalomyelitis (ME). People with ME finally had the possibility of significant research funding from the government through the ME/CFS Delivery Plan. With no money allocated in the Delivery Plan hopes of progress dwindled.

#MEAction UK used #MillionsMissing to campaign to get research into ME fully funded in the final ME/CFS Delivery Plan. We asked people to use our tools and their own imagination to craft an SOS and send it to the government, the Medical Research Council (MRC), Department of Health and Social Care (DHSC) and the National Institute for Health and Care Research (NIHR).

#MEAction Scotland

The Scottish Government included £4.5m in the Scottish Budget to deliver specialist support for Long Covid, ME and other similar conditions #MEAction Scotland's Millions Missing rally outside the Scottish Parliament aimed to put pressure on the Scottish Government to set out how they will use the funding to develop services.

Eighteen MSPs from across the political spectrum came out to support us, with MSPs from each party giving a speech at the event and highlighting their support for people with ME and commitment to helping the community.

The Minister for Public Health and Women's Health, Jenni Minto MSP, also spoke and confirmed the government's discussion with Scottish Health Boards on how the allocated funding could be spent. She highlighted that the NICE Guideline should be followed over the, now outdated, Scottish Good Practice Statement which meant that, after years of campaigning by #MEAction Scotland, the Government had finally committed to the NICE Guideline.

Education of Healthcare Professionals

In March 2025 we organised and ran an information stall at the Royal College of Paediatrics and Child Health (RCPCH) conference with the aim of talking to paediatricians and explaining how they can help children and young people with ME. The RCPCH is the membership body for paediatricians in the UK and around the world, with about 24,000 members in the UK and internationally. They focus on postgraduate medical education, professional standards, research and policy.

There were very high levels of interest from both medical students and paediatricians, particularly in NICE key symptoms. We were delighted to have Helen Brownlie, 25% Group and Dr Nigel Speight, consultant paediatrician who specialises in ME helping at the stand (see photo below). Over the two days of the conference, we engaged with over 300 delegates.

In May 2025 our response to the recent opinion piece, 'Patients with severe ME/CFS need hope and expert multidisciplinary care' in the BMJ was published. We were disappointed by the BMJ's commissioning and publication of this opinion piece which

advances a biopsychosocial framework for ME that is outdated, unscientific, and potentially harmful, especially for those with severe and very severe illness. Read MEAction UK's response.

#MEAction Scotland's volunteers ran three clinical awareness sessions: a GP study group, a GP practice in East Lothian and a Medical English group for refugee doctors. We also ran a session for the GPs at Edinburgh University Health Centre in April 2025.

#MEAction Scotland continues to be involved in the Learn About ME project managed by Action for M.E. to ensure more doctors understand ME/CFS. Other partners in the project are Dr Nina Muirhead, a dermatology consultant who has ME, and the ME Association. With funding from the Scottish Government, the Learn About ME project is promoting Dr Muirhead's free CPD-accredited learning module on ME/CFS.

Campaigning for Effective Support

We continued to support the campaign to highlight the flaws in Cochrane's stance on reassessing its exercise therapy review for ME/CFS. We supported a petition to request an update of the description of ME/CFS in Kumar and Clark's Clinical Medicine textbook.

In January 2025 the original analysis, with its methodological flaws and omission of key data, remained entirely unchanged – except for its publication date. Cochrane edited it to read 2024: a decade after any of the peer-reviewed sources cited. This undermines public trust in research and highlights the need for a more ethical and inclusive approach to systematic review.

Building a Stronger Community

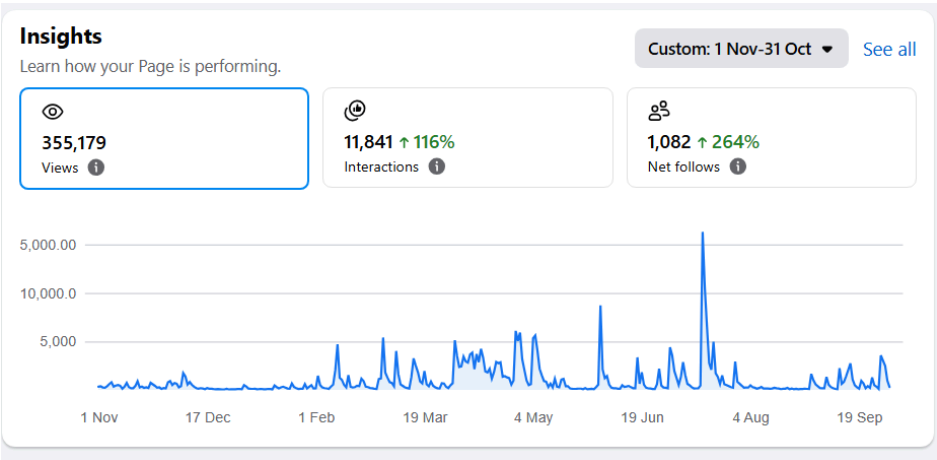
We were one of 15 organisations backing a new policy brief calling on the government to commit to an NHS that's there for Long Covid and ME. The policy brief is part of #ThereForME, a new campaign calling for an NHS that's there for people with ME and Long Covid. We asked the government to commit to an NHS that is there for people with ME and Long Covid and put this into action by prioritising publication of the cross-government delivery plan on ME/CFS.

We shared the call to the ME Community to help gather more signatures on this petition for an Urgent Call for the Creation of an NHS Protocol for Severe Myalgic Encephalomyelitis (ME).

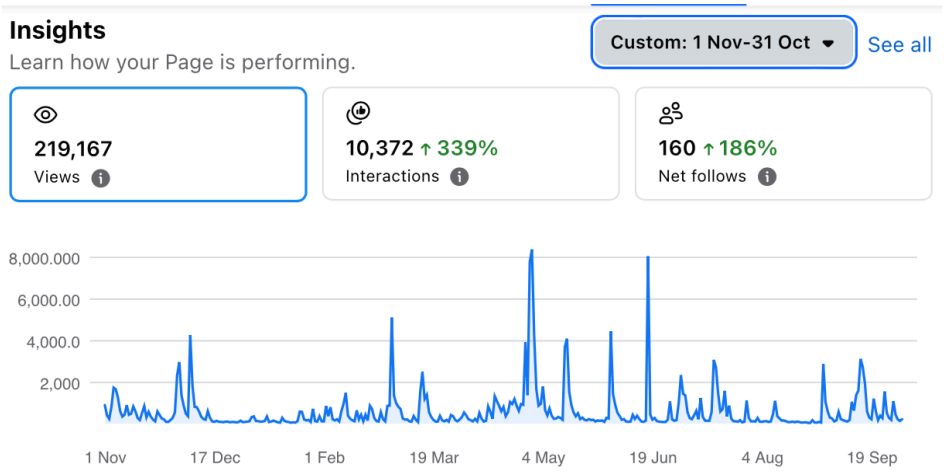
We continued to campaign for Karen Gordon, an ME patient in hospital at risk of starvation due to lack of total parenteral nutrition or tube feeding.

We use Facebook, X, Instagram, Bluesky and LinkedIn and have channels for the UK and Scotland. Our engagement on social media is climbing as illustrated by our Facebook statistics.

Facebook posts in the UK



Facebook posts in Scotland



The pilot of the Scottish Volunteer Network has proved successful in engaging with a wider group of volunteers and providing a resource for specific projects. We plan to extend the network in Scotland and launch a similar initiative in the rest of the UK. The Volunteer Network is an inclusive way of involving our ME supporters, allowing them to contribute to our campaign as their capacity allows. It also helps us to tap into the wealth of experience, skills and wisdom within this community. Network members have provided us with case studies, written to their MSPs, taken part in media interviews, reviewed documents, taken part in consultations and given us feedback throughout the year.

Promoting Research

We appealed to the UK community to sign an urgent letter to the U.S. National Institutes of Health (NIH), demanding that the NIH fund the ME/CFS Research Roadmap. The roadmap was developed by a working group of foremost experts on ME and community members (including #MEAction). The roadmap outlines how to advance ME/CFS research with a focus on delivering clinical trials. However, the NIH has dedicated no money to fund this critical roadmap.

With 96 per cent accuracy, a new blood test offers hope for those living with chronic fatigue syndrome - which is often misunderstood and misdiagnosed.

We contacted the team behind research into a blood test for ME at the University of East Anglia and Oxford BioDynamics. By examining 3D genomic folds the team revealed hundreds of changes, including five of the eight sites identified by DecodeME. Each of our cells contains about two metres of DNA, packed tightly and folded in 3D. These folds aren't random - millions of them are deliberate, forming a hidden code that helps turn genes on or off to keep us healthy. The team discovered a unique pattern that appears consistently in people with ME/CFS that is not seen in healthy people.

We agreed to work with them to provide patient perspectives as they undertake further trials.

https://www.news-medical.net/.../Scientists-develop-a...

Financials

Purposes, Aims and Public Benefit

MEAction UK became a charity on 5th April 2023. The charity supports the wider #MEAction network and fights for recognition, education, and research so that one day all people with ME (myalgic encephalomyelitis) and other complex, chronic post infectious illnesses will have access to rapid diagnosis, and compassionate, effective care. We campaign on the issues that are most pressing. Further information regarding our activities can be found on our website.

Our vision is a world where people with ME are believed, supported by systems that work and have access to effective medical treatments.

Financial Review

The Trustees were pleased to receive a major donation which has enabled them to employ professional management tools and plan significant actions. They are satisfied with the financial position of the charity.

Policy on reserves

We would like to keep reserves to cover 3 months of activities.

Statement of Financial Activities for the Year Ended 31 October 2025 (including Income and Expenditure Account and Statement of Total Recognised Gains and Losses)

These are the figures for the previous accounting period and are included for comparative purposes

	Note	Unrestricted funds £	Total 2024 £
Income and Endowments from:			
Donations and legacies	2	1,179	1,179
Total income		1,179	1,179
Expenditure on:			
Charitable activities	6	(244)	(244)
Total expenditure		(244)	(244)
Net income		935	935
Net movement in funds		935	935
Reconciliation of funds			
Total funds brought forward		545	545
Total funds carried forward	9	1,480	1,480

Balance Sheet

	Note	2025 £	2024 £
Current assets			
Cash at bank and in hand	7	28,260	1,480
Creditors: Amounts falling due within one year	8	(1,056)	-
Net assets		27,204	1,480
Funds of the charity:			
Unrestricted income funds			
Unrestricted funds		27,204	1,480
Total funds	9	27,204	1,480

For the financial year ending 31 October 2025 the charity was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

Directors' responsibilities:

- The members have not required the charity to obtain an audit of its accounts for the year in question in accordance with section 476; and
- The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

These financial statements have been prepared in accordance with the special provisions relating to companies subject to the small companies regime within Part 15 of the Companies Act 2006.

Public benefit

The trustees confirm that they have complied with the requirements of section 17 of the Charities Act 2011 to have due regard to the public benefit guidance published by the Charity Commission for England and Wales.

Trustees

The Trustees, for the purposes of Charity law and under the Company's Articles, are known as members of the Board of Trustees. Under the requirements of the Memorandum and Articles of Association, the members of the Board of Trustees are elected to serve for a period of three years. Retiring Trustees may be re-appointed but no Trustee may serve for more than two consecutive terms of office, save that the Trustees may decide that there are exceptional circumstances which mean that it would not be in the best interests of the Charity for a Trustee to take a break from office and resolve that the Trustee may serve for a third term of office.

As the charity is also a Company Limited by Guarantee, the Trustees are also Directors of the Company.

There are no paid members of staff of the charity and all Trustees work voluntarily for the charity and receive no remuneration.

The trustees serving during the year and since the year end were as follows:

Denise Spreag, Chair Appointed 2/10/22

Malcolm Bailey Appointed 2/10/22

Janet Sylvester Appointed 2/10/22