#MEAction UK & #MEAction Scotland's Annual Report

November 2023 -October 2024

Overview

MEAction UK is a UK charity and our work centres around empowering/enabling people with 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.

In the UK we are run entirely by volunteers who have ME or have a close relation/friend with ME. We have no paid staff Everything that MEAction UK has achieved this year has been as a result of the outstanding efforts and hard work of our dedicated trustees and volunteers. #MEAction UK and #MEAction Scotland are the working names of the charity.

Parliament

Throughout the year we galvanised support from MPs and MSPs and campaigned for change from the Westminster and Holyrood governments and publicly funded organisations.

Following a meeting with Jenni Minto, the Scottish Government's Minister for Public Health and Women's Health, in October 2023 to brief her on the urgent need for support for people with ME, #MEAction Scotland provided briefings to MSPs in all four main parties to submit Parliamentary Questions (PQs) on the key issues discussed with the Minister. PQs submitted between January and March 2024 included questions on the implementation of the NICE guideline in Scotland, particularly around the recommendations for those with severe ME; the publication date for the NHS Education for Scotland training module on ME; the Government's commitment to research funding following the publication of the JLA PSP; the timetable for establishing a stakeholder group to ensure people with ME had the support they needed from Health Boards; and how the Government planned to fill the gap in services for children and young people with ME.

Department of Health and Social Care - DHSC

In August 2023 the DSHC launched a consultation on the interim delivery plan on ME/CFS. The consultation was to seek views on an interim set of actions to improve the experiences and outcomes of people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and it will inform the development of a final cross-government delivery plan on ME/CFS. Our volunteers were members of working groups and took part in workshops.

Awareness and Public Understanding

We used social media, media coverage and our online presence to raise awareness of the debilitating impact of ME and the best approaches to managing the disease and to call for the hundreds of millions of pounds missing from research into ME.

We also featured The ‘Blue Sunday’ Tea Party For M.E. on our social media and encouraged people to join in the virtual tea party started by Anna Redshaw.

In January 2024 we shared the deep concerns of the ME community about a segment featured on an episode of Dragons' Den, which aired on BBC1 on Jan 18th 2024. The episode in question showcased a product “Acu Seeds” that had a back story where the entrepreneur said she “believed they had aided in her recovery of ME/CFS”.

#MEAction UK and #MEAction Scotland co-signed a letter, produced by Action for M.E., to the Chair of the Culture, Media and the Chair of the Sport and Health and Social Care Committee setting out our concerns and the danger of media organisations promoting unfounded health claims. We also wrote to the BBC and the production companies involved with this programme. As a result of campaigning the BBC edited the episode of Dragon's Den that featured Acu Seeds. The BBC said "a clarification has been added to the programme on iPlayer to address the concerns raised".
A text statement is now displayed on screen while Ms Boxer is seen pitching her Acu Seed business. It reads: "Acu Seeds are not intended as a cure for any medical condition and advice should always be sought from a qualified healthcare provider about any health concerns."

We complained to The Telegraph about Judith Woods' Comment piece on 2nd February 2024, '28-year-old Lauren Hoeve died by euthanasia – to a degree, I understand her pain' where she asserted that a great deal of Lauren's anguish was 'psychological'.

In a Channel 4 News piece about DecodeME in early April 2024, #MEAction Scotland volunteer, Jo Bruce, pointed out that people like her, with severe ME, have been crying out for funding for biomedical research for years and hoped that the DecodeME study would be the start of a breakthrough in ME research.

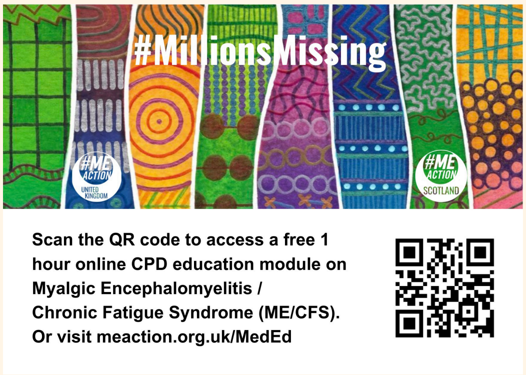
MEAction UK trustee Denise Spreag was quoted in this Daily Mirror article in April about the treatment of those with very severe ME in hospital. "Millie's treatment is extremely worrying and is making Millie's very severe ME much worse. Unfortunately, this pattern of ignoring the updated NICE guideline on ME and treating this disease using the outdated, discredited and dangerous idea that it is a mental illness/eating disorder has already caused great harm to people suffering the most severe form of this devastating illness.

"We urge those involved in treating Millie to follow the NICE guideline, published after rigorous analysis of the science. They must listen to the ME experts, stop inappropriate treatment and treat people with ME and their families with humanity."

#MillionsMissing

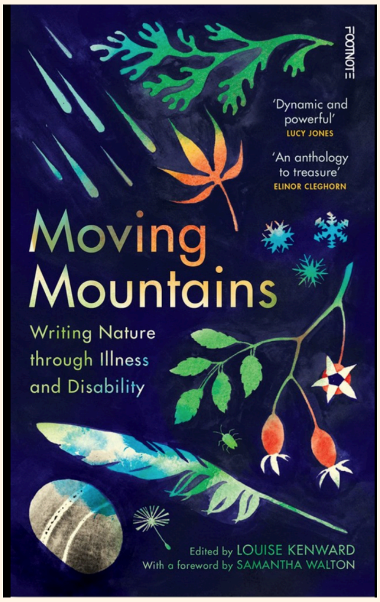
The theme for #MillionsMissing was #TeachMETreatME. This global #MEAction initiative to raise awareness among medical professionals of the challenges faced by those with ME and emphasise the critical need for healthcare education about this debilitating condition.

Our ‘Postcards to Doctors’ campaign was a key element #MillionsMissing 2024 across the UK. Members of the community were encouraged to send postcards to their doctors or local GP surgeries, urging them to learn about the complexities of ME. A key resource was Dr Nina Muirhead’s one-hour CPD module on ME. When sent on a large scale, these postcards made the fact that every GP and practice has multiple patients living with ME inescapable, and highlighted that there are resources available that can make a difference.



Scan the QR code to access a free 1 hour online CPD education module on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). Or visit meaction.org.uk/MedEd

As part of #MillionsMissing we recorded and edited readings from the Moving Mountains anthology, introduced by Louise Kenward. Through twenty-five pieces, the writers of Moving Mountains offer a vision of nature that encompasses the close up, the microscopic, and the vast.



We provided help and information to David Spencer, whose daughter Kara Jane, died from ME. He handed out hundreds of leaflets educating visitors and staff about ME at King's Mill Hospital and Sherwood Forest Hospitals NHS Foundation Trust.

As a direct result of #MEAction Scotland's Millions Missing campaign in May 2023, the Royal College of Physicians Edinburgh ran a webinar on ME/CFS and Long Covid in June 2024. #MEAction Scotland volunteer, Karima Rahman spoke at the webinar which 265 RCPE members attended live and a further 83 registered to catch up in the following months.

Education of Healthcare Professionals

Following #MillionsMissing actions in May 2023 outside The Royal College of Physicians Edinburgh the Dean of Education identified the lack of training on ME/CS and organised a webinar on ME and Long Covid which was held in June 2024. Speakers at the webinar included a volunteer from #MEAction Scotland and the Scientific Director from #MEAction.

Throughout the year #MEAction Scotland has been involved in a project managed by Action for M.E. to ensure more doctors understand ME/CFS. Partners in the project are Dr Nina Muirhead, the ME Association and 25% M.E. Group. With funding from the Scottish Government's Neurological Framework, the Learn About ME project is promoting Dr Muirhead's free CPD-accredited learning module on ME/CFS.

We collaborated on the Learn about M.E. podcast series, featuring Consultant Respiratory Physician Dr Binita Kane and parent Helen Gibson. Both highlight the need for specialist support and understanding for children and young people who live with M.E.

Helen Gibson, a volunteer for #MEActionScotland, a member of M.E. Parents, and

Mum to a 17-year-old-daughter with M.E., also shares her family's experience. She explains how her family have had to develop an expertise on the illness far beyond that which most patients/carers would expect, a direct result of M.E. being so poorly understood.

In spring 2024, nearly 30 medical students from across Scotland took part in the inaugural Learn about M.E. essay competition which was won by Bhanu Wahi-Singh, a fifth year medical student at The University of Edinburgh.

Building Community

Using social media, including Facebook groups, we have provided support for people with ME and information and advice for those wishing to volunteer with #MEAction UK.

We campaigned on behalf of those severely and very severely affected by ME.

We continue to support the campaign to help a young woman with very severe ME, Karen Gordon, to get her adequate care. Sadly, Karen was admitted to hospital and is still there and her petition still needs support.

We promoted the exhibition of a talented member of the ME community in August 2024. Billie M Vigne is an artist and metalsmith who has lived with ME/CFS for 25 years.

We prepared a list of hints, tips and resources to help people with ME over the Christmas holidays.

In February the final pre-inquest hearing into Maeve Boothby O'Neill's tragic death from ME began. We attended remotely and kept the ME community updated.

We shared a petition organised by ME Foggy Dog that calls for the creation of a protocol for Severe ME.

Starting in February 2024 we promoted a petition on behalf of Millie, who has very severe ME/CFS. After campaign the hospital confirmed that the NICE guidelines have now been read and the staff are trying to follow them. Millie's ME is being believed. Millie's family is now allowed to be with her at all times and advocate and support her.

Promoting Research

Raising awareness of the need for research into the cause of ME and potential treatments/cures by encouraging people with ME to contact research funders and promoting the results of research.

We also supported DecodeME through our social media channels. DecodeME is the largest research project to date that is investigating the causes of ME/CFS.

Decode ME

The ME/CFS Study

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 and those of MEAction partners can be found on our website MEAction UK

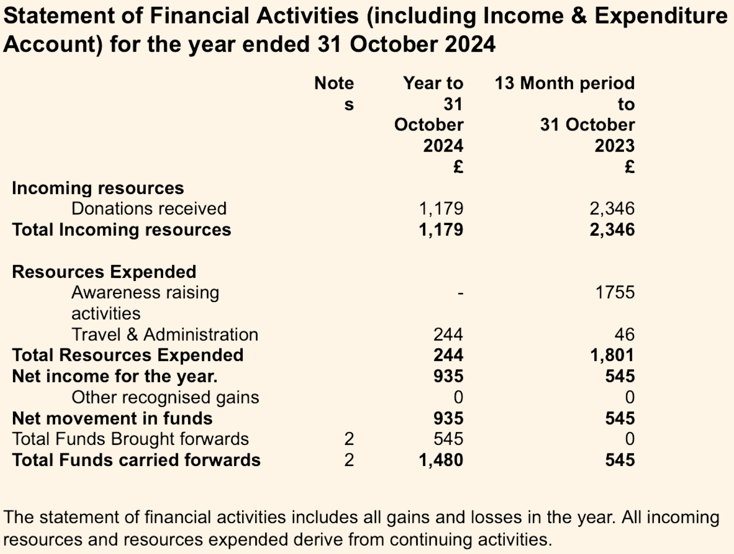
Our vision is a world where people with ME are believed, supported by systems that work and have access to effective medical treatments.

Financial Review

During this first period of accounts the charity has received unrestricted donations from individuals and has incurred limited expenditure in the course of its awareness raising and other activities.

The charity has no employees and its directors have received no remuneration.

Statement of Financial Activities

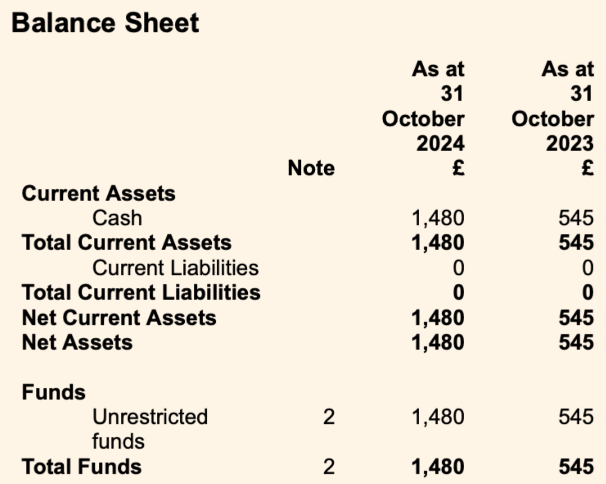


Statement of Financial Activities (including Income & Expenditure Account) for the year ended 31 October 2024

	Notes	Year to 31 October 2024 £	13 Month period to 31 October 2023 £
Incoming resources			
Donations received		1,179	2,346
Total Incoming resources		**1,179**	**2,346**
Resources Expended			
Awareness raising activities		-	1755
Travel & Administration		244	46
Total Resources Expended		**244**	**1,801**
Net income for the year.		**935**	**545**
Other recognised gains		0	0
Net movement in funds		**935**	**545**
Total Funds Brought forwards	2	545	0
Total Funds carried forwards	2	**1,480**	**545**

The statement of financial activities includes all gains and losses in the year. All incoming resources and resources expended derive from continuing activities.

Balance Sheet



Balance Sheet

	Note	As at 31 October 2024 £	As at 31 October 2023 £
Current Assets			
Cash		1,480	545
Total Current Assets		**1,480**	**545**
Current Liabilities		0	0
Total Current Liabilities		**0**	**0**
Net Current Assets		**1,480**	**545**
Net Assets		**1,480**	**545**
Funds			
Unrestricted funds	2	1,480	545
Total Funds	2	**1,480**	**545**

These accounts are prepared in accordance with the special provisions of Part VII of the Companies Act 1985 relating to small entities.

For the year ending 31 October 2024, the company was entitled to exemption from audit under section 477 of the Companies Act 2006 relating to small companies.

The members have not required the company to obtain an audit of its accounts for the year in question in accordance with section 476.

The directors acknowledge their responsibilities for complying with the requirements of the Act with respect to accounting records and the preparation of accounts.

Public benefit

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. This annual report contains a fuller description of the public benefit that MEAction UK provides.

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.

Governing document

The organisation is a charitable company limited by guarantee and is a registered charity in England and Wales. The Company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association.

Legal and administrative Information

Name

MEACTION UK

#MEACTION UK (Working name)

#MEACTION SCOTLAND (Working name)

Company number:

14391671

Charitable Objects

THE OBJECTS OF THE CHARITY ARE, FOR THE BENEFIT OF THE PUBLIC, THE PROVISION OF RELIEF, THE ADVANCEMENT OF HEALTH, AND THE ADVANCEMENT AND PROMOTION OF EDUCATION IN CONNECTION WITH MYALGIC ENCEPHALOMYELITIS ("ME") (ALSO KNOWN AS CHRONIC FATIGUE SYNDROME) AND OTHER COMPLEX, CHRONIC ILLNESSES INCLUDING POST INFECTIOUS ILLNESSES IN PARTICULAR BUT NOT EXCLUSIVELY BY: (A) RAISING AWARENESS AND PUBLIC UNDERSTANDING OF ME AND OTHER COMPLEX, CHRONIC ILLNESSES (INCLUDING BUT NOT LIMITED TO LONG COVID); (B) PROVIDING INFORMATION, ADVICE AND SUPPORT; AND (C) ADVANCING RESEARCH INTO ME AND OTHER COMPLEX, CHRONIC ILLNESSES (PROVIDED THAT THE USEFUL RESULTS OF ANY SUCH RESEARCH ARE DISSEMINATED TO THE GENERAL PUBLIC).

Trustees and Directors 2023 – 2024

Denise Spreag

Appointed 02/10/2022

Malcolm Bailey

Appointed 02/10/2022

Janet Sylvester

Appointed 02/10/2022

Laura Jones

Appointed 02/10/2022

Resigned

Registered Address: 10 Belsize Park Mews, London NW3 5BL.