



#MEAction UK & #MEAction Scotland's Annual Report



October 2022-October 2023

Overview

MEAction UK's 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.

This was a landmark year for us. We incorporated as a company in October 2022 and registered as a charity operating throughout the UK in April 2023, arranged multiple #MillionsMissing demonstrations across the UK, campaigned for the hundreds of millions of pounds missing from research into ME, lobbied the Scottish Parliament to implement the NICE guideline in Scotland, worked to update the education of healthcare professionals, challenged misinformation about ME and used social media to communicate and build community. Our work was featured in publications ranging from the BMJ and the Journal of Neurology, Neurosurgery & Psychiatry, to The Shetland Times.

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.

Parliament

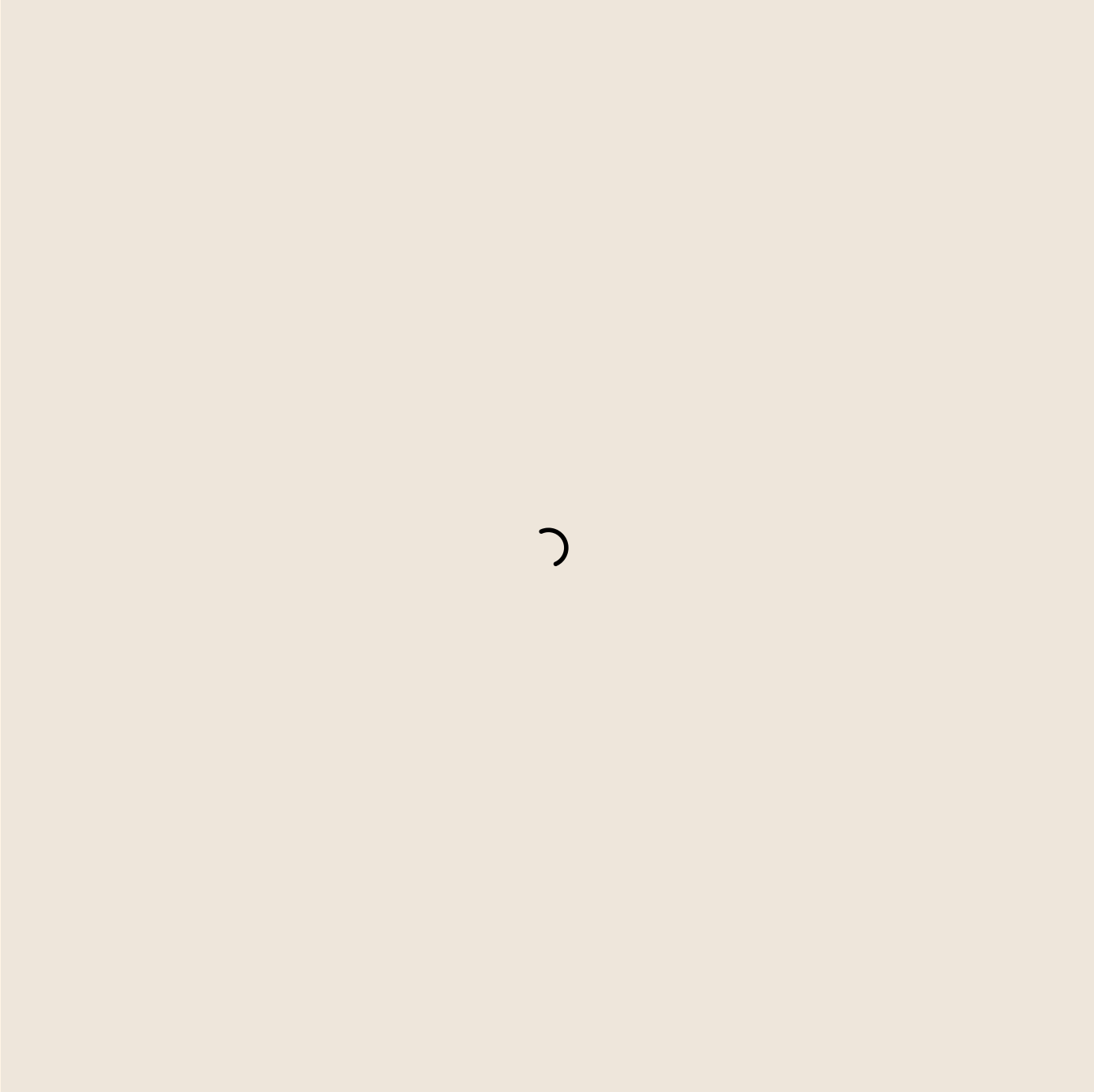
Throughout the year we galvanised support from MPs and MSPs and campaigned for change from the Westminster and Holyrood governments and publicly funded organisations.

In October 2022 #MillionsMissing UK took place in Parliament Square. We were delighted to get so much support from MPs from all sides of the House.

Emma Lewell-Buck MP, Hywel Williams MP and Alex Chalk MP, Emma Lewell-Buck MP, Hywel Williams MP, Ben Lake MP, Alex Chalk MP, Fleur Anderson MP, Ben Bradshaw MP, Lord Bethell and Baroness Scott of Needham Market all accepted our invitation.



In February 2023 a Members' debate on ME took place in the Scottish Parliament. The debate was led by Sue Webber MSP, working in partnership with [#MEAAction Scotland](#). MSPs from all parties spoke, many of them quoted the stories of their constituents who had contacted them following a campaign on MEAction Scotland's social media.



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We have continued to work closely with Sue Webber and key MSP champions in the main parties to make sure that the voices of people with ME are heard in the Parliament where possible.

In May 2023, following the debate on ME in the Scottish Parliament, Sue Webber hosted an #MEAction Scotland #Millions Missing lunchtime event in the Parliament. #MEAction Scotland volunteers engaged with MSPs, telling them about the urgent changes needed for people with ME in Scotland.



ME is
career-er
life-destro
disability.

MILLIONSM

25%
PEOPLE WITH
M.E ARE
HOUSEBOUND
OR
BEDBOUND

#MILLIONSMISSING

In October 2023 #MEAction Scotland volunteers met with Jenni Minto MSP, Minister for Public Health and Women's Health, along with staff from the Scottish Government's Clinical Priorities team. The volunteers briefed the Minister on the key issues for people living with ME, and asked her to take urgent action to implement the NICE guideline in Scotland and fund training and education for healthcare professionals based on its recommendations. The urgent need for support for people with ME, including children and young people was also discussed.



In August 2023 the DHSC 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.

To help people navigate the consultation process we held an online community call to give an overview of the DHSC's interim delivery plan and gather thoughts and input on the consultation. We then put together [resources](#) to help people respond to the DHSC survey on the ME/CFS interim delivery plan.



SUBMITTING YOUR OWN RESPONSE

- The more responses the better!
- Don't be intimidated. You are the expert on your experience of ME.
- You **do not** have to answer all the questions.
- You can do it in chunks and your answers will be saved.
 - Copy the address of the page you are on from the address bar in your browser, save it/bookmark it to return to it.
- You can request a paper copy by emailing mecfs@dhsc.gov.uk, or someone can do this on your behalf.
- #MEAction webpage with FAQs and preview of questions:
<https://www.meaction.net/2023/08/10/dhsc-consultation-faq>

We then prepared our own detailed responses to DHSC (My Full Reality: The Interim Delivery Plan On ME/CFS) for #MEAction [UK](#) and #MEAction [Scotland](#) in time for the October deadline.

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.

In October 2022 the [BMJ](#) reported on London's #MillionsMissing demonstration in Parliament Square, the @bmj_latest shared an article covering the action.

"Demonstrators in London's Parliament Square last week called for hundreds of millions of pounds missing from research into myalgic encephalomyelitis to be restored to the condition."



The [Canary](#) also covered London's #MillionsMissing demonstration in Parliament Square.

Chronically ill people have had to protest yet again for basic support

'Chronically ill, disabled people have once more taken to protesting. They're calling for funding for medical research into their disease, known as ME. It's one that the state, medical professionals, and society have neglected for decades. So, 'millions of missing people' came together online and in person to demand change. And they were also asking for support from one specific organisation: the Wellcome Trust.'

Following the February 2023 debate in the Scottish Parliament, volunteer Helen was on Good Morning Scotland talking about the need for healthcare education and funding to improve support for people with ME. Beatrice Wishart MSP was highlighted in the [Shetland Times](#) for speaking in the debate. Even though some of the language used by the journalist in this article isn't helpful, it's still good to get people talking and reading about ME:

MSP wants action to make a difference for ME sufferers



Kevin Craigens

February 2, 2023



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SHARE ON:



Shetland MSP Beatrice Wishart

A review on Chronic Fatigue Syndrome will need to make a difference for those who suffer from it to make it worthwhile, according to MSP Beatrice Wishart.

In April 2023 [STAT](#) published a searing investigation about the US National Institutes of Health's failure to make progress on Long COVID. Adam Lowe, #MEAAction UK volunteer spoke with the journalists and explained why an exercise trial would be such a disaster. "What often happens is, people will go for a walk, they may not feel it for a day or two, and then suddenly, they feel ill on the third day."

A STAT INVESTIGATION

The NIH has poured \$1 billion into long Covid research
— with little to show for it

By Rachel Cohrs Zhang and Betsy Ladyzhets April 20, 2023



RECOVER has persistently ignored the advice from both the ME/CFS and Long COVID communities to build off the existing knowledge and expertise on post-infectious disease.

Studying exercise as a treatment could "frame long Covid as something that can be overcome with grit and hard work," said Jaime Seltzer, the director of scientific and medical outreach at MEAction, arguing that such framing is "unsound and ethically troubling."

We promoted Bake4ME/CFS, a SPACE themed cakes competition. The competition was judged by actress Jennie Jacques, Alyssa Carson, space enthusiast and astronaut in training, Kat The Baking Explorer blogger.

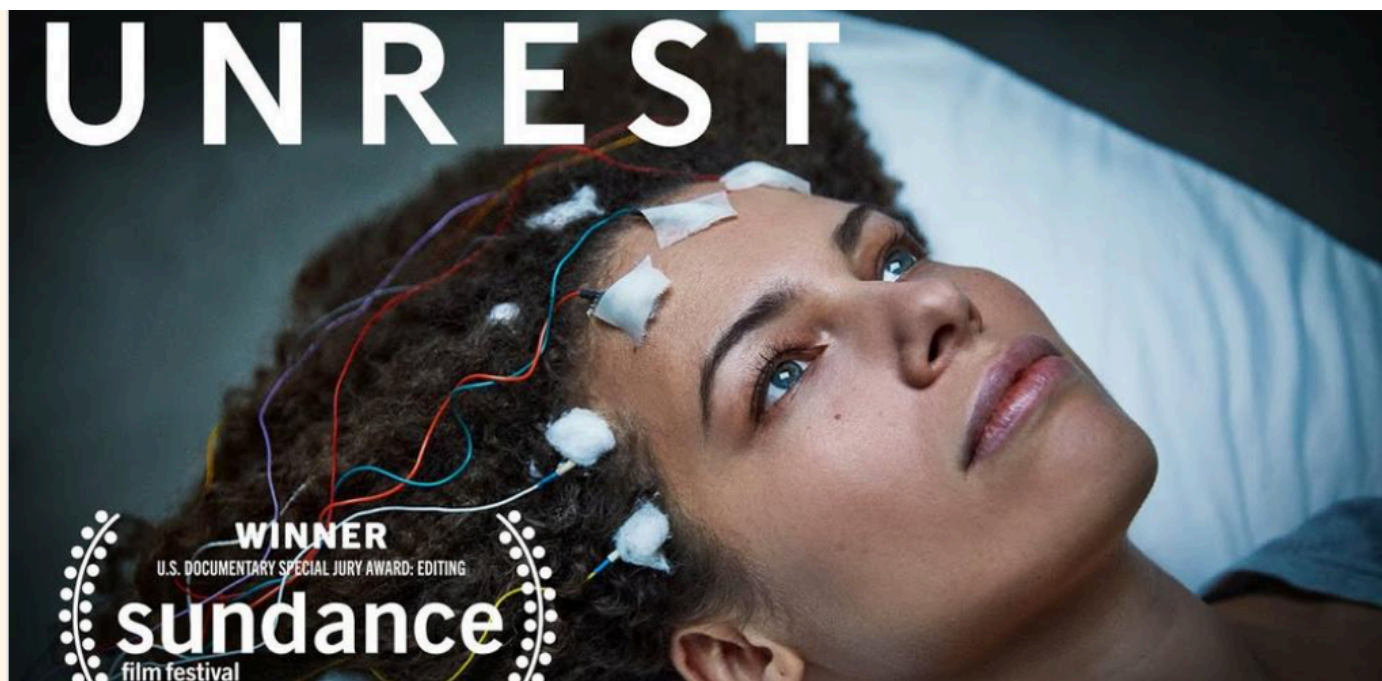
We also featured The 'Blue Sunday' Tea Party For M.E. on our social media and encouraged people to join in the virtual tea party started by Anna Redshaw.



#MEAction Scotland were [featured](#) on STV News on 11th May 2023, calling for funding and healthcare education on ME. They highlighted doctors' lack of knowledge about ME and the need for training to recognise key symptoms and understand current guidance.



In June we promoted a free streaming of [Unrest](#) on YouTube. Sundance award winning Unrest is a powerful campaigning tool. It features twenty-eight year-old Jennifer Brea who is working on her PhD at Harvard and months away from marrying the love of her life when she gets a mysterious fever that leaves her bedridden and looking for answers. Disbelieved by doctors yet determined to live, she turns her camera on herself and discovers a hidden world of millions confined to their homes and bedrooms by ME, commonly known as chronic fatigue syndrome.



#MEAAction UK prepared a detailed response to the latest published paper attacking the NICE Guideline on ME/CFS in July. We also responded to The Guardian in [reply](#) to their article covering the publication.

#MEAAction UK submitted a rapid [response](#) to the article, 'Anomalies in the review process and interpretation of the evidence in the NICE guideline for chronic fatigue syndrome and myalgic encephalomyelitis' published in the Journal of Neurology, Neurosurgery & Psychiatry published 10th July 2023. Our response was published in July and then removed. We challenged the grounds for this and were pleased when it was reinstated with a few selected edits, in September 2023, as it's important to have our response to the article on the record and permanently attached to the article.

We also joined with 55 organisations, researchers, clinicians and advocates in firm support of the 2021 NICE guideline on ME in signing the World ME Alliance's rapid response to the JNNP article.

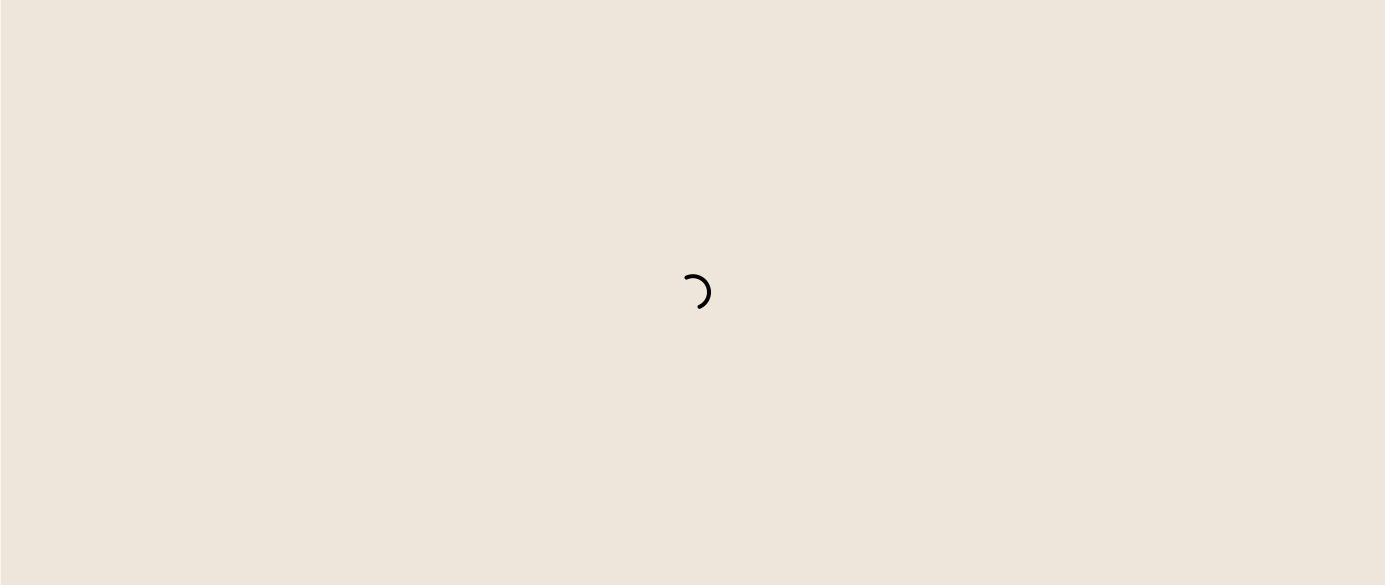
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**organisations, researchers,
clinicians and advocates**

#MillionsMissing

We coordinated annual awareness raising events across the UK, including successfully moving from in-person to virtual events during Covid-19. This was a busy year for us with #MillionsMissing UK events in October 2022, moved from September due to the death of Queen Elizabeth, and another in May 2023.

#MillionsMissing October 2022



#MillionsMissing London took place in Parliament Square on 18th October 2022 and demanded the millions of pounds missing from ME research in the UK. We asked all our supporters, people with ME and people with other complex chronic conditions to lobby the Wellcome Trust, the biggest funder of medical research in the UK, to commit significant funding to ME.

We were delighted to get so much support from MPs. Emma Lewell-Buck MP, Hywel Williams MP and Alex Chalk MP, Emma Lewell-Buck MP, Hywel Williams MP, Ben Lake MP, Alex Chalk MP, Fleur Anderson MP, Ben Bradshaw MP, Lord Bethell and Baroness Scott of Needham Market all accepted our invitation.

Sarah Boothby's daughter, Maeve Boothby O'Neill, died from ME last year. Sarah spoke about their experiences and the neglect they faced from the medical establishment.

Hayley Valentine-Howard spoke about ME and pregnancy. Prof Douglas Kell talked about his groundbreaking micro clot research in ME and Claire Tripp gave an update

about Decode ME. Lord Bethell and Fleur Anderson MP for Putney both spoke about their support for people with ME and Long Covid and the #MillionsMissing.

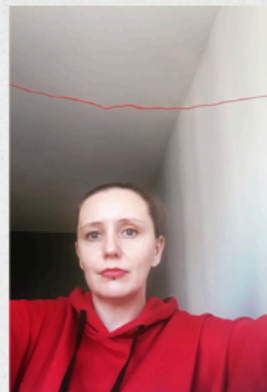
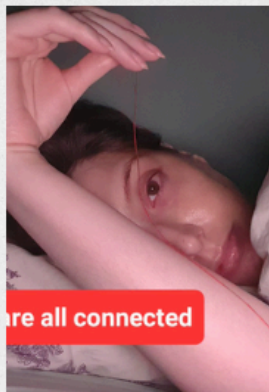


Our Virtual Action.

We asked supporters to post pictures of a red thread to illustrate how #WeAreAllConnected for #MillionsMissing and to contact the [Wellcome Trust](#) and tell them why we need the hundreds of millions of pounds missing from ME research.

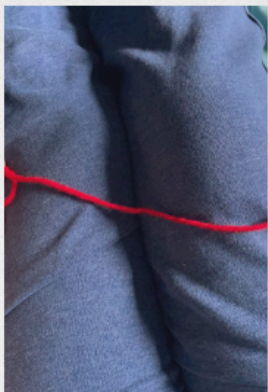


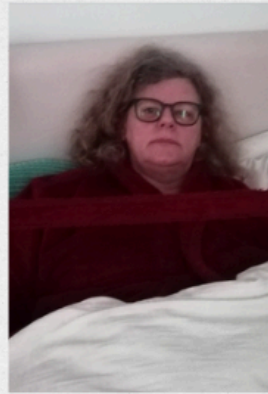
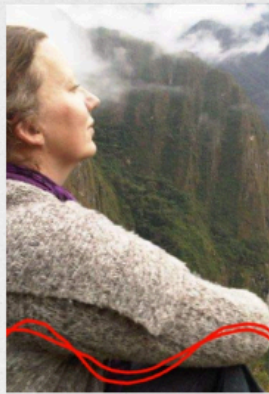
#MILLIONS MISSING



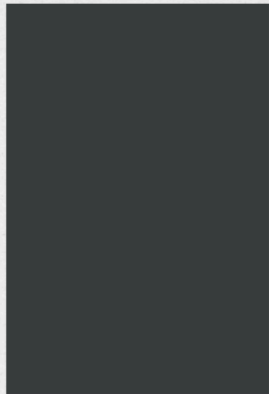


#MILLIONS MISSING





#MILLIONS MISSING



Following #MEAction Scotland's #MillionsMissing action at the end of September 2022, we continued to contact MSPs asking them to sign a pledge in support of people with ME. By the end of October, a total of 24 MSPs signed the pledge, this represents one in five MSPs in the Scottish Parliament.

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#MillionsMissing May 2023

We asked people to get creative (or to ask someone else to on their behalf) for #MillionsMissing and join us in asking society, #CanYouSeeMENow?

#MEAction UK and #MEAction Scotland volunteers teamed up to run a digital campaign that returned to the central theme of #MillionsMissing – amplifying the people missing from their previous lives and wider society because of ME.

There were two different concepts for photos. The first option was to take a photograph of the view that a person with ME sees every day. The second option was to take a photo that showed the spaces that people are missing from.

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Education of Healthcare Professionals

Working with other charities we promote relevant training modules to healthcare professionals and have got agreement for the development of an ME module for GPs in Scotland.

In November 2022 Caroline Kingdon's new [paper](#), 'What Primary Care Practitioners Need To Know About The New NICE Guideline For Myalgic Encephalomyelitis/Chronic Fatigue Syndrome In Adults' on the NICE guideline for ME was co-written with #MEAAction UK volunteer Adam Lowe, as well as Charles Shepherd of the ME Association and Luis Nacul of the London School of Tropical Medicine.

NHS Education for Scotland (NES), the education and training body for NHS Scotland, released a draft training module on ME/CFS in November 2022. This module is part of a programme of Practice Based Small Group Learning topics (PBSGL) developed by NES and the issuing of the draft was the culmination of years of campaigning by #MEAAction Scotland, in partnership with Action for M.E. Whilst this has been a frustratingly slow process we are pleased that our efforts have finally paid off.

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



On 16th May 2023, the Scottish Government published the findings from an analysis of surveys issued to NHS Health Boards to understand delivery of ME services and implementation of the updated NICE guideline. The report was commissioned as a direct result of #MEAAction Scotland volunteers meeting the then Cabinet Health Secretary in September 2022 as part of our campaign to get the NICE guideline implemented in Scotland.

In October 2023 #MEAAction UK and Scotland organised and attended a stall at the Royal College of General Practitioners's Annual Conference in Glasgow. Alongside Action for M.E, we spoke to hundreds of GPs over the three days of the conference, focussing on raising awareness of the 2021 NICE guideline and other available resources that can improve how they diagnose and support people with ME.



Throughout the year #MEAAction 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.

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 #MEAAction UK and #MEAAction Scotland.

Thanks to the hard work of the volunteers on our social media team our social media reach increased with our UK Facebook reach up by 80% to 62,200 and visits up 385% to 5,400. Instagram reach increased by 240% to 11,300 and visits were up 452% to 3,500.

Scotland's reach also increased with Facebook reach up almost 70% to 24,800 and visits increased by 192% to 24,800. Instagram reach was up 138% to 6,100 and visits increased by 202% to 831.

We campaigned on behalf of those severely and very severely affected by ME. In January 2023 we honoured the [memory](#) of the amazing Kara Jane, who was an extremely talented musician. It's heartbreaking to have lost such an incredible light who fought so hard for the ME community. Her legacy and music will live on.



In February 2023 Sami Berry was severely ill in an NHS hospital and very concerned that she was going into intestinal failure and was at immediate risk of joining those with severe ME and complex chronic illness who have died under the negligence of the NHS. Maeve Boothby O'Neill, Merryn Crofts, and Sophia Mirza are three recent examples. #MEAAction UK sent out a press release to help apply pressure on the hospital to get her the care she deserved. The situation in the hospital reached the point that Sami decided she had to self-discharge to try and stay alive.



Shortly after, Alice, another woman with severe ME in a UK hospital needed help. A member of Alice's family reached out and asked us to share a [petition](#).



In March 2023, due to community action Alice's feeding regime was [changed](#).

In September 2023 another woman with very severe ME, Karen Gordon, was at risk and we promoted a [petition](#) to get her adequate care. Sadly, Karen was admitted to hospital and is still there.

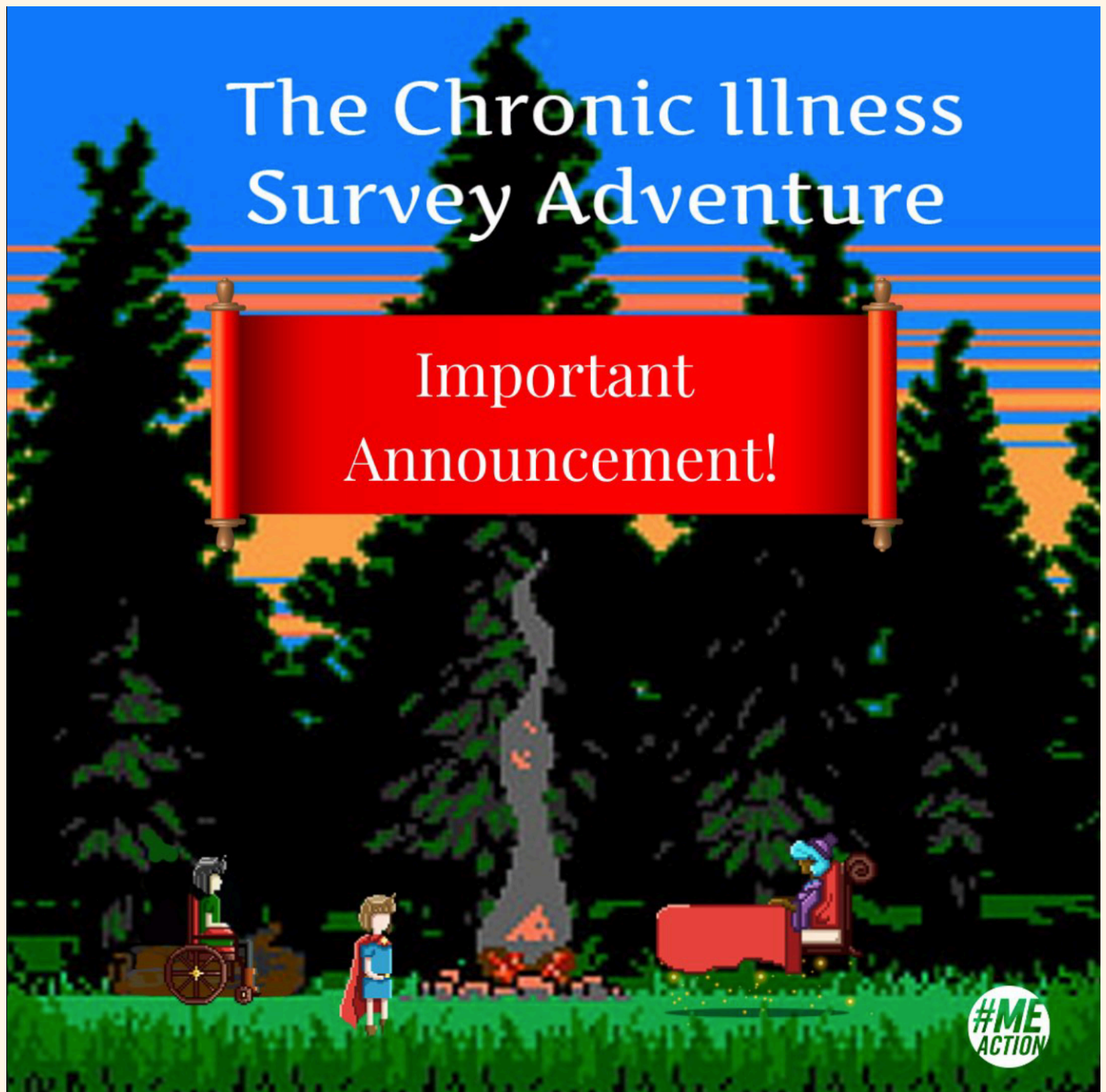


September 2023 we supported a [petition](#) started by Science for ME asking Cochrane to withdraw the harmful 2019 Exercise therapy for CFS review.

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 supported, #MEAAction's ambitious project, the Chronic Illness Survey [Adventure!](#) The Adventure is a survey to deeply examine the symptoms experienced by people with diseases that are triggered or unmasked by infection, including ME, POTS, hEDS, MCAS, and Long COVID.



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

The ME/CFS Study



For #MillionsMissing in Parliament Square on 18th October 2022 we asked all our supporters, people with ME and people with other complex chronic conditions to lobby the Wellcome Trust, the biggest funder of medical research in the UK, to commit significant funding to ME.



Financials

Purposes, Aims and public benefit

MEAction UK was incorporated on 2 October 2022. The organisation 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

These accounts are the first accounts since the charity was incorporated on 2 October 2022. 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 (including Income & Expenditure Account) for the 13-month period ended 31 October 2023

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

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

These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies’ regime.

Approved by the management committee on 1st July 2024 and signed on its behalf by: Denise Spreag, Chair of Trustees

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 2022 – 2023

Denise Spreag

Appointed 02/10/2022

Malcolm Bailey

Appointed 02/10/2022

Janet Sylvester

Appointed 02/10/2022

Laura Jones

Appointed 02/10/2022

Adam Lowe

Appointed 02/10/2022

Resigned 12/03/2023

