

IMPACT
STATEMENT
March 2022-May 2023

#### **OUR AIM: Implementation of the NICE Guideline on ME/CFS**

In September 2022, #MEAction Scotland met with, then Cabinet Secretary for Health, Humza Yousaf. This led to him commissioning <u>a report</u> into ME services across Scotland.

In February 2023, MSP Sue Webber led a Parliamentary debate on the lack of services available to people with ME in Scotland.

Following the debate, our volunteers met with Minister for Public Health, Maree Todd.

We have since attended regular meetings with the government's Clinical Priorities Team.

### CAMPAIGNING FOR EFFECTIVE SUPPORT

## SCOTTSH PARLAMENT

#### A summary of our action and impact in numbers

- MSPs met with our volunteers to discuss the desperate situation for people with ME in Scotland.
- Parliamentary debate led by Sue Webber MSP, where 11 MSPs told powerful stories from constituents.
- 24 MSPs signed our pledge calling for services for people with ME.
- 41 MSPs engaged with our cause.
- 28 Parliamentary Questions were specifically asked about ME by 7 different MSPs.

#### Supporting the education of health and social care professionals:

#MEAction Scotland became a key partner in Action for M.E.'s project to promote Dr Muirhead's CPD training module across Scotland. Our volunteers participated in one of Action for M.E.'s podcasts for healthcare workers 'Learn about ME'. We were also involved in developing the Neurological Alliance of Scotland's Self-Directed Support leaflets for health and social care professionals.

### **#MEAction Scotland submitted responses to a number of important consultations:**

Adult Disability Payment (ADP) Mobility Component, Disability Commissioner Bill, Covid 19 recovery group, Long Covid inquiry, the <u>National Discussion on Education</u> in Scotland.

#### **#MEAction Scotland met with Social Security Scotland:**

We highlighted issues with the ADP guidelines for people with ME and people with other energy-limiting conditions. We put together some examples of how they could improve them to incorporate into ADP guidance. This has created real change, as Social Security Scotland is now working on implementing these.

### CAMPAIGNING FOR EFFECTIVE SUPPORT



# 3 Millions Missing events

September 2022 - We held a demonstration outside Holyrood, attended by more than 120 people.

May 2023 - We held a demonstration outside the Royal College of Physicians Edinburgh (RCPE).

May 2023 - We held a drop-in event for MSPs to learn more about our cause, attended by 20 MSPs.

### CREATING STRONGER ADVOCATES

## RASMG AMAREMESS

of the devastating effects of ME

#### Our actions resulted in:



Articles in national press: Daily Record, Scottish Daily Express, Sunday Express, The Independent, The Times, The Scotsman, The National And in local press: Edinburgh Evening News, Glasgow Evening Times, Central Fife Times (plus other local newspapers outside of Scotland)



Featured on BBC Radio Scotland



**Discussed on STV News** 

#### 6.1K Total social media followers

Broken down per channel, that looks like:

2.9k on Facebook

**2**k on x

1.2K on Instagram

## BUILDING OUR GOMMUNITY

#### HIGHEST PERFORMING POSTS



It's #MillionsMissing! A day to raise awareness of the millions of people the world missing from their lives due to ME, and to demand better.

This morning, #MEAction volunteers were outside The Royal College of Physicians of Edinburgh. We handed out information about ME to doctors of into the building, displayed photos of people with ME's views from their be and delivered a letter to the Dean of Education asking for the development training on ME in line with the 2021 NICE Guideline.

#CanYouSeeMEnow #MyalgicEncephalomyelitis #pwME #MEAwarenessWe



**Facebook** 4.6k impressions



X (formerly Twitter) 27.9k impressions



meactionscotland · Following

#### meactionscotland 80w

The team of volunteers organising #MillionsMissing Scotland are very aware that joining the protest isn't possible for lots of people with ME, and we want to make sure your voices are heard.

So we want to know - if you could be with us, what would you say? Comment, DM or email us at scotland@meaction.net with a couple of lines of text that you want people at the event to know, and we'll collect them and read them out on the day 💗

ID: A mass lie down at a Millions Missing protest. People lying down on the floor are filling the space outside a building.









September 7, 2022



Add a comment..



Instagram 1.3k impressions

## MHO WE ARE

#MEAction Scotland is run entirely by unpaid volunteers. We have a core team of 6 and a further 12, made up of people with ME and carers, who are unable to contribute regularly but help when they can.

If you are interested in getting involved, or want to get in touch with us about something else, feel free to email scotland@meaction.net.