

COME WORK WITH US

Trustee

Play a critical part in providing support to people with M.E. while working to support change for the future

Recruitment Pack
February 2024

Welcome to Action for M.E.

Thank you for considering joining Action for M.E. as a Trustee.

We deliver services to support the needs of children and adults with M.E. while working to secure change for the future.

We are a small organisation that regularly punches above its weight, working on a national and international scale. We are delighted to be working with a staff, volunteer, and Board of Trustees team who are passionate, dedicated and determined.

We have high aspirations and ambitions and our strategy is one for growth so that we can reach more people and accelerate breakthrough in research.

We believe that Action for M.E. can, and will, make a major contribution to creating the change that is so desperately needed.

We look forward to hearing from you.



Sonya Chowdhury
Chief Executive



Roger Siddle
Chair, Board of Trustees



“Action for M.E. is a hugely positive place to turn to when there is nowhere else to go.”

“Thousands of silent M.E. sufferers rely on Action for M.E.”



Action for M.E. is the only UK charity supporting children and adults with M.E. through information, support, advocacy and healthcare services while working to secure change for the future.

www.actionforme.org.uk

WHAT IS M.E.?

A neurological illness with symptoms that affect at least 1.3m children and adults in the UK alone. Investing in M.E. research, support and care 30 years ago could have made a massive impact for people suffering with mirroring M.E. symptoms in Long Covid now

M.E. – the facts



1 in 4 people are so severely ill they are house/bedbound for years, even decades.

M.E. is the biggest cause of health-related, long-term school absence.

Parents are threatened, unnecessarily, with child-protection action because M.E. is misunderstood; many stop work to provide full-time care for their child.

Suicide

Suicide risk is six times higher than average, for people with M.E.

Quality of life is desperate, worse than many conditions including congestive heart failure and MS

Less than 1 in 10 adults with M.E. can work part-time, with a conservative cost to the economy estimated at £3.3bn a year.

M.E. & Long Covid

- At least 1.3m people with M.E. or Long Covid symptoms that directly mirror M.E.
- Before Covid, an estimated 250,000 people had M.E. in the UK; this number has grown exponentially
- Long Covid is an overlapping illness with M.E. – 1 in 5 doctors are unable to go back to work or have had to reduce working hours, with almost 50% losing earnings
- The cost to the economy of M.E. alone was conservatively estimated to cost £3.3bn. This is now much higher.

“After six months off work, she [Dr Amy Small] eventually lost her job because her condition left her unable to keep up.”

“It was devastating, my husband also had Long COVID, at the time that I lost my job, his pay was halving, my roof was leaking, I had to pay for a kid in full-time nursery **and we risked losing everything at that point.**

I really thought we were going to lose our house, we were really facing really, really challenging times.”

Sky News, 4 July 2023

What does M.E. feel like?

Sam tells us:

“It’s like having glandular fever, taking your glandular fever on an all-night drinking binge, then taking your glandular fever and your hangover and doing a 30km forced march over the Brecon Beacons. The way you would feel at the end of that is how it feels to have M.E. every day. It is like being on a carousel: you have ups and downs but you can never get off.”

Another Action for M.E. supporter says:

“I feel like I wake up with a mattress on me most mornings. When I wake up with post-exertional malaise, there is an elephant sitting on the mattress. He stays there for days. He steals my words and fills my brain with wet cotton wool and wraps his trunk around my neck, so I struggle to swallow.”

Our ambitions



Ambition 1

The lives of people with M.E. are improved by effective access to information, support and advocacy they need.



Ambition 2

The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence (NICE) guideline for M.E. being effectively implemented across NHS services.



Ambition 3

Increased funding for high-quality research by more researchers leads to effective treatments for M.E.



Ambition 4

The UK Government establishes and leads a national strategy for M.E.

Delivering Our Ambitions - Our Services



Information, Support & Advocacy Services

We provide direct services for children and adults with M.E. and their families, including:

- Information and support via phone, email and text alongside a range of resources and tools to ensure people have the access to the information they need at a time they need it most
- One-to-one advocacy to improve access to support and care they need
- Our InterAction Magazine for adults which is often described as a lifeline by many
- Family support to enable families to best meet their children's needs
- Online support forums for children/young people and for adults to reduce isolation and provide peer support
- Children's Services including a Birthday Card Scheme to ensure every child receives at least one card from their peers, a pen-pal service to reduce isolation and loneliness, and our Cheers magazine, produced by young volunteers, which helps create a sense of community and provides skills to include on CVs for the future.

Holistic Healthcare Services

We provide paid-for online healthcare with bursaries, where needed, including:

- GP services for initial and ongoing support
- Physiotherapy appointments
- Counselling for adults to support people's emotional and mental health
- Multi-faith Chaplaincy to support emotional and spiritual well-being
- Children & Young People's Counselling Service, a free, confidential service about to launch.



Delivering Our Ambitions - Accelerating Change



Accelerating Research

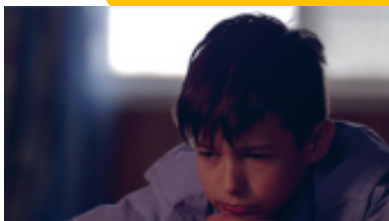
Our Breakthrough-ME Research Strategy sets out a bold, ambitious plan to accelerate research to identify diagnostics and treatments. There has been a paucity of research funding, a lack of researchers in the field and therefore a lack of research, so our understanding and knowledge of the causes, diagnosis and potential treatments is poor. All our activity has involvement of people with lived experience at its heart to enhance the scientific value of research. Our current activities include:

- Co-delivering the world's largest M.E. study, DecodeME, with 26,000+ UK participants, of which, 21,000 were invited to provide DNA samples to help uncover the biological causes of M.E. and a new partnership to enhance diagnostics and treatments in M.E. and Long Covid
- Co-establishing a Genetics Centre of Excellence for M.E. to increase research, funding and the number of researchers in the field
- Supporting a Future Leaders' Network of early-stage career researchers including through PhD studentships and Fellowships
- Forging new partnerships and collaborations, including with corporates, to bring in new funding and interest to accelerate research.

Public Affairs & Communications

We worked to secure the ME/CFS Interim National Delivery Plan and have continued to support development of the final Plan which is to be launched soon. Alongside this, we:

- Provide the Secretariat for the All Party Parliamentary Group (APPG)
- Have launched a Parliamentary Champions Scheme, to sustain profile and focus on M.E. in both Houses, alongside ongoing work with parliamentarians
- Undertake a wide range of press and media work to raise understanding of M.E.
- Are about to launch a campaign to ensure diagnoses of M.E. is coded correctly on people's primary healthcare records to support gaining a better evidence base & ensure continuity of care.



Trustee role description

Duties of a Trustee are as follows:

- To ensure that Action for M.E. complies with its Memorandum and Articles of Association, charity law, company law and any other relevant legislation or regulations
- To ensure that Action for M.E. pursues its charitable objects as defined in its Memorandum of Association
- To ensure Action for M.E. applies its resources exclusively in pursuance of its objectives
- To contribute actively to the Board of Trustees role in establishing a clear and shared vision for Action for M.E., giving firm strategic direction, setting overall policy, defining goals, setting targets and evaluating performance against the agreed targets
- To act in the interests of Action for M.E. and for people with M.E. in general
- To safeguard the good name and values of Action for M.E.
- To ensure the effective and efficient administration of Action for M.E.
- To ensure the financial stability of Action for M.E.
- To protect and manage the property of Action for M.E. and to ensure the proper investment of charity funds
- To appoint the Chief Executive and to monitor his or her performance and determine his or her remuneration
- In addition to the above statutory duties of all Trustees, each Trustee should use any specific knowledge or experience they have to help the Board of Trustees reach sound decisions
- To represent Action for M.E. as appropriate.

Time Commitment

The time commitment expected of a Trustee is approximately six days per annum, including an AGM, preparing for and attending Board meetings, and involvement in at least one of the sub-committees: Audit, Finance & Fundraising; Public Affairs & Communications; Research; Healthcare Services; or Remunerations & Nominations.

We hold an away day once every two years. Additional time may be required dependent on circumstances/needs. You will receive a full induction and support upon appointment.

We do ask that Trustees make a commitment to at least one, three-year term of office.

Person Specification

All Trustees must demonstrate:

- A commitment to the organisation, its cause and demonstrate an understanding of M.E. and its impact
- A willingness to devote the necessary time and effort
- Strategic vision
- Good, independent judgment
- An ability to think creatively
- A willingness to speak their mind
- An understanding and acceptance of the legal duties, responsibilities and liabilities of Trusteeship
- An ability to work effectively as a member of a team
- A willingness to participate in at least one sub-committee, as appropriate
- A commitment to working within Action for M.E.'s values and principles of working, including Nolan's 'Seven Principles of Public Life':
 - a. Selflessness
 - b. Integrity
 - c. Objectivity
 - d. Accountability
 - e. Openness
 - f. Honesty
 - g. Leadership.

Specific requirements:

We regularly review the skills and backgrounds of our Board members and are specifically looking for people who bring:

- Scientific and/or research expertise
- Policy experience at local or national level
- Local government experience
- Communications expertise.

How to Apply

If you are interested in becoming a Trustee, please submit:

- Your CV, including all employment/voluntary roles since you left full-time education ensuring any gaps or time out is accounted for and
- A completed 'Equal opportunities monitoring and information form' (provided separately)
- A covering letter outlining why you would like to become a Trustee and how you meet the person specification outlined above, including how you meet the specific requirements we are currently looking for.

Please also indicate any reasonable adjustments that you may require to enable us to provide a good recruitment process with you.

Applications should be sent to charlotte.wells@actionforme.org.uk by 5pm 30 April 2024.

You will be informed of the outcome of your application and any potential interview dates with the Chair, the Chief Executive and another Trustee. We will be inviting people for interviews as applications come in and will close recruitment when we fill the current vacancies.

Further information

If you have any questions or would like an informal discussion, please contact either:

- Sonya Chowdhury, Chief Executive at ceo@actionforme.org.uk; or
- Roger Siddle, Chair at chair@actionforme.org.uk

Equity of access

We strive to ensure equity which includes being as accessible as possible to attract Board members with a diverse range of experience and insight. If you don't meet the person specification fully, please do consider contacting us for a discussion as you may be our ideal candidate!

We will consider all requests for reasonable adjustments within the parameters of ensuring Trustees are able to enact their legal responsibilities and accountabilities.

Joanna's story



"I went from being a young, active, recently qualified social worker, newly married with our first home, looking forward to the future and enjoying lots of outdoor and social activities, to being asleep in bed, unable to even carry out a conversation, walk, care for myself and feeling very confused about what was happening and fearful of what the future holds. Any hope of how my life would be was shaken and I felt I lost my core sense of self and identity."

Joanna has used most of the services offered by Action for M.E., including our Healthcare Services, launched in March 2022. "I have found them to be invaluable resources for dealing with the challenges of severe chronic illness that has left me bedbound. The wide spectrum of support covering the physical, mental and emotional, spiritual and social aspects has made a huge difference to how I feel and cope with the difficulties I face on a daily basis, along with practical management advice from the Information and Support services who have signposted me to additional resources I need. The complementary nature of the Counselling and Chaplaincy services has had such a positive impact on my overall wellbeing as they approach issues from their own unique perspectives, and together give a more holistic picture." Action for M.E.'s M.E. Friends Online forum in particular has given Joanna a place where she can share her experiences, and feel understood. "I can offer support to other people to help satisfy a little of my need to feel useful, if I have anything to offer to make them feel better. Since having severe M.E. has meant losing my friends, family and social community, I feel I have gained a vital place to turn to with people who understand, so I don't have to try to cope alone anymore."



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