

Action for M.E. DecodeME Recruitment and Support Worker Application Pack



Thank you for considering joining Action for M.E.

I joined Action for M.E. in September 2012 and am delighted to be working with a staff and volunteer team and Board of Trustees who are passionate, dedicated and determined.

Our 2016 – 2021 strategy, launched at our 2016 AGM and conference, sets out how we meet need now to improve the lives of people with M.E. while taking action to secure change for the future.

A small organisation that regularly punches above its weight, we are leading, with others, a growing community of supporters working to create real change on the scale so urgently needed at a local, national and international level.

In April 2017, we launched our Children's Services after joining forces with national children's charity, the Association of Young People with M.E. This provides an exciting opportunity to raise more money to reach more people and raise much needed awareness and understanding

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



Sonya Chowdhury
Chief Executive

Our values

Shared values are held with high regard in our organisation and reflect how we seek to work with our supporters, partners and other key stakeholders. They reflect the attitudes, beliefs and behaviour that we value in each other and underpin our whole approach and culture.



About us

Action for M.E. takes action to end the ignorance, injustice and neglect that people with M.E. face day-in, day-out.

The charity was founded by Sue Finlay in 1987 and since then has been working tirelessly to tackle the inequality experienced by people with M.E.

M.E. (Myalgic Encephalomyelitis) is a chronic, neurological illness affecting an estimated 250,000 adults and children in the UK. It may be diagnosed as Chronic Fatigue Syndrome (CFS, or M.E./CFS).

People with M.E. experience severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in symptoms.

Even in its so-called mildest form, M.E. can have a significant impact on an individual's life, and not just on their health. A lack of understanding and awareness about M.E. means patients can experience disbelief, and even discrimination, from friends, family, health and social care professionals, employers and teachers.

Our vision

A world without M.E.

Our mission

Empowering people with M.E. to fulfil their potential and secure the care and support they need, while working towards a greater understanding of the illness and ultimately a cure.

Our people

President

Clare Francis MBE

Vice President

Martin Arber

Patrons

Lord David Puttnam CBE

Lord Melvyn Bragg

Julie Christie

Alan Cook CBE

Chair of Board of Trustees

Roger Siddle

Vice Chair

Alison Deeth

Board of Trustees

We are an organisation led by people affected by M.E. for people affected by M.E. We aim to have a minimum of 51% of our Trustees who have, or have had, M.E. themselves.

Our Trustees are unpaid and meet at least four times a year and many sit on one of our four sub-committees. Board meeting location alternates between London and Keynsham.

We have a staff team of 29 (22 FTE) and approximately 70 volunteers who support our work in a number of different ways.

Our head office is in Keynsham (between Bath and Bristol) and we also have a small number of staff and volunteers in Scotland and a staff member in East Midlands.

Our purpose is to end the ignorance, injustice and neglect experienced by people with M.E.

Children, young people and adults with M.E. are at the heart of everything we do. We asked and we listened, and have identified a number of challenges that continue to exist for people affected by M.E.

Everything we do over the next five years will be in service of achieving three goals, which we call our strategic touchstones.

By collaborating with those who share our vision and purpose, we make the most of the resources available to us.

Around 50% of our activities will directly focus on targeting information, improving support and reducing isolation to **IMPROVE** the lives of children, young people and adults with M.E.

To be as effective as possible, 30% of our activities will focus on facilitating more action, more influence and better understanding of M.E. to **INSPIRE** action at all levels; and 20% of our activities will be focused on bringing more research, more money and more people into the field to **INVEST** in change.



Job summary

Job title	DecodeME Recruitment and Support Worker
Responsible to	Research Officer
Responsible for	N/A
Salary	£14,330
Hours of work	21 hours per week for 12 months
Annual leave	30 days + eight bank holidays per year; pro rata
Location	Keynsham office or home-based anywhere in the UK

Job purpose

You will play a vital role in supporting the recruitment of 20,000 participants to, and marketing of, the DecodeME study; the world's largest DNA study. Responding to general enquiries about the project and taking part, you will interface directly with research participants who have been diagnosed with Myalgic Encephalomyelitis/ chronic fatigue syndrome (ME/CFS). Working alongside patient and public involvement (PPI) members and other partnership colleagues you will also provide direct support to the project team and its various working groups.

Key duties

Recruitment of research participants

- Respond to general enquiries about the project either by phone, email or on social media
- Respond to specific enquiries from potential participants either by phone, email or on social media
- Support the Communications and Marketing Officer in promoting the DecodeME project using social media- e.g. Twitter, Facebook, LinkedIn
- Support the work to plan, create and contribute to audience-appropriate, user-led, outcome-focused content for our digital channels, including social media; our e-updates using SendinBlue; and our DecodeME website, using Wordpress

Working with others

- You will support the Marketing and Communications Group and Cohort Delivery Group on various discrete tasks
- You will provide support to DecodeME Partnership colleagues, including the researchers, PPI and the PR and digital marketing agencies to facilitate an integrated and cohesive project planning and delivery
- You will support the Communications and Marketing Officer in engaging with the DecodeME Social Media Ambassadors, working with them and other

partnership colleagues to secure a broad and diverse reach across the ME/CFS community, including those that we are not currently actively engaged with, and the people who may be working with/supporting them

- As you will also be part of the Action for ME team, you will work with colleagues across the charity, to maximise the outputs for the study and ensure mutual benefit for the charity and people with ME/CFS

Other key accountabilities

- Build relationships with key stakeholders and other charity professionals, to support collaborative working
- Contribute to tracking management information data and outcome measurement to ensure ongoing review and evaluation of our communications, marketing and engagement work
- Ensure best value in all service/project delivery
- Act as an advocate for DecodeME, the charity and its work, and contribute to raising the profile of ME/CFS
- Work collaboratively across the DecodeME project team and the charity including staff, volunteers and Trustees, and with key external stakeholders including people affected by M.E.
- Keep up-to-date with and ensure best practice is observed; comply with relevant legislation and regulatory requirements, working within the charity's policies and procedures, including those relating to safeguarding, health and safety and data protection are met.
- Undertake any other duty within your ability and within reason, as may be required from time to time, at the direction of your line manager. This includes cover for team members who are away.

Person specification

Qualifications

- Minimum grade 9-5 GCSE English and Maths (essential)
- Degree level in a biomedical (or related) science subject (desirable)

Essential/ desirable experience and knowledge

- Strong interpersonal, written and verbal communication skills (essential)
- Experience of working with personal or other sensitive data (essential)
- Demonstrable experience of working across a range of social media channels (essential)
- Experience of working in patient/ public involvement and an ability to work alongside people as equal partners (essential)
- Demonstrable experience of engaging with an online community, ideally within a disability, science or health context (desirable)
- Knowledge and understanding of the impact of long-term health conditions such as ME/CFS (desirable)
- Demonstrable experience in a marketing and/or communications role (desirable)

Skills and behaviours

- Excellent written and verbal communication and interpersonal skills, including a good telephone manner
- Ability to engage face-to-face, by phone and online with stakeholders at all levels, to build relationships and create a sense of community
- Ability to source and produce dynamic, engaging, outcomes-focused content, tailored to the needs of our audiences, taking a story-telling approach
- Ability to maintain a high degree of accuracy and attention to detail
- Ability to use own initiative, work independently and to work well in a team
- Strong MS Office skills (including Teams, Word, Excel, databases) and web-related programmes and software; experience of media monitoring software (desired but not essential)
- Proficient and experienced in the use of IT systems such as MS Office (including Outlook, Word and Excel), client databases/casework management systems, and using the internet
- A strong, demonstrable understanding of meaningful patient and public involvement and an ability to work alongside people as equal partners
- Excellent planning skills with the ability to work methodically, managing and prioritising a varied workload

Attitudes and values

- Self-starter
- Able to give and receive constructive feedback
- Collaborative work attitude
- Enthusiastic and inclusive
- Acts with integrity
- Adaptable and flexible
- Calm, compassionate, empathic and patient
- Resilient and resourceful

Key competencies

- Confident communicator
- Thrives on attention to detail
- Strategic thinker
- Outcomes-focused
- Strong team player

Terms and conditions

Outlined below are some of the main terms and conditions of employment relevant to all employees of Action for M.E.

1. Notice

Temporary contracts have one-weeks notice on either side in lieu of a probation period.

2. Annual leave

The hourly rate for temporary contracts includes an annual leave allowance.

3. Pension scheme

Action for M.E. operates a group pension scheme on an auto-enrolment basis. All employees will join the scheme on the completion of the probationary period unless they choose to opt-out. Action for M.E. will pay a pension contribution which is currently 4% of salary. Action for M.E. will not pay into a personal pension scheme

4. Salary payment

Salaries are paid in arrears on the last working day of each month, by direct credit transfer into a bank or building society.

5. Flexibility

Some posts may require working outside of normal office hours and travel to attend meetings and events within the UK, including occasional overnight stays.

Application timetable

Deadline for applications	Monday Noon 16 th August 2021
Short list meeting	Tuesday 17 th August 2021
Interviews (to be held over zoom)	Tuesday 24 th and Wednesday 25 th August 2021

How to apply

To apply, please follow the below link to our application form via Google Forms:
<https://forms.gle/kqL1DCD5Ca79quRP6>

For more information, or to submit an application, please contact Stacey Vincent at Action for M.E., 42 Temple Street, Keynsham BS31 1EH. Tel: 0117 927 9551.
Email: recruitment@actionforme.org.uk



Cover image shows, top left to right: Jake, Ian, Paul, Dan, Chris, Rich and Matt who ran and cycled the virtual length of America's Route 66 highway – 2,280 miles - to raise £4,500 for Action for M.E.; Christmas Angels knitted by our supporters to send to young people with the condition; the ME/CFS Priority Setting Partnership research project logo; Olivia, who has had M.E. for ten years, taking part in our 2021 #yearsinelockdown campaign.

Bottom left to right: Prof Chris Ponting, patient representative Andy Devereux-Cooke, Solve ME/CFS Chief Scientific Officer Dr Sadie Whittaker and Action for M.E. CEO Sonya Chowdhury at a webinar for DecodeME, the world's largest M.E. DNA study; the campaign banner for our Big Give Christmas Challenge; the cover of *InterAction*, our membership magazine, described by many readers as a lifeline.