

# Action for M.E. Research Director 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.

We aim to 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 began supporting children and young people with M.E., after joining forces with national children's charity, the Association of Young People with M.E. In January 2022, we began offering Healthcare Services following our merger with the ME Trust. 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 purpose

We take action to end the ignorance, injustice & neglect experienced by people with M.E.

## 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 40 (28 full-time equivalent) 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 have colleagues all over the UK working from home.

## Breakthrough-ME: driving research to end M.E.

Despite the devastating impact of M.E., understanding of the disease is still woeful. While at least 250,000 people live with M.E., and even more experiencing overlapping symptoms with M.E. following Covid, we have no treatments and little understanding of its causes. Significant investment in high-quality research is critical.

Action for M.E. has worked hard to improve the lives of children and adults with M.E., but this is not enough. To end the neglect of M.E. we need a national strategy that includes a focus on research.

Our goal is to achieve a breakthrough in M.E. research that will provide the scientific knowledge required to deliver the diagnostics, treatments and eventually cures that we so desperately need.

Partnering with Prof Chris Ponting (Medical Research Council's Human Genetics Unit and Principal Investigator on DecodeME), Action for M.E. will:

- **Host a genetics research summit to stimulate new studies.** We will bring together leading biomedical researchers and people with lived experience of M.E. this year. The summit will focus on genetic research and knowledge gained from other post-infectious diseases including Long Covid.

- **Establish the first Genetics Centre of Excellence.** We will establish a virtual network of M.E. researchers to work with the M.E. community, to build on the genetic insights gained through DecodeME and other studies. We will establish a programme of high-quality research, supported by the Centre of Excellence.

Breakthrough-ME will ensure that people with lived experience are at the heart of all research delivered through the Centre of Excellence. We will build on the patient and public involvement that is driving the **DecodeME study** and the **M.E./CFS Priority Setting Partnership**.

We want to see the same level of funding and high-quality research as in other severe diseases. We will work across other scientific disciplines to accelerate our ability to pursue research leads as they emerge.

We will invest in a Future Leaders programme to create a pathway for early-stage career researchers to secure funding and stay in the field.

## Job summary

<b>Job title</b>	Research Director
<b>Responsible to</b>	CEO
<b>Responsible for</b>	Research team – currently Communications and Marketing Officer, DecodeME Study; Research Officer
<b>Salary</b>	£50,000
<b>Hours of work</b>	Full time (35 hours per week)
<b>Annual leave</b>	30 days + 8 bank holidays per year pro rata
<b>Location</b>	Home based or Keynsham office

## Job purpose

The purpose of this role is to lead and deliver an exciting and transformative research strategy to provide greater understanding of ME while working towards treatments and eventually a cure.

## Detailed role description

### Key duties

- To lead the day-to-day work around our research programme and implement the research strategy, engaging and integrating the work across the organisation
- Through the research we fund, but also through maximising our influence of others, ensure that our research strategy is implemented effectively
- To appreciate the value of and ensure that meaningful patient and public involvement is at the heart of our research activity
- To provide leadership and strategic direction for Action for M.E.'s research function across the organisation
- As a member of the Senior Leadership Team, to contribute to the leadership, strategy, planning and policy formulation of the organisation as a whole and deliver our organisational objectives
- To represent the organisation externally, taking a key role in stakeholder management including build and foster collaborative working relationships with the research and academic community, funders and donors, government and others.
- Lead on new partnerships, initiatives and developments including
  - the Genetics Research Centre of Excellence in partnership with the MRC Human Genetics Unit, University of Edinburgh,
  - securing programmes of research for the Top 10 Priorities for ME Research, an output from a James Lind Alliance Priority Setting Partnership, and
  - delivery of the DecodeME Study.



- Work with the CEO, colleagues, our Honorary Scientific Adviser and the Research Board Sub-Committee to ensure on-going development of our research strategy
- Regularly review all relevant national and international published research, to develop and maintain the required expertise on research in the organisation. Provide update briefings to Action for M.E. staff on key research developments as appropriate
- Undertake periodic 'futures research' review to identify opportunities, gaps, threats and risks in ME research
- Ensure our grant processes support our objectives of funding high quality biomedical research
- Work on an evolving pipeline of researchers and build ME research infrastructure prospects from the ground up

### **Working with others**

- Support the organisation's fundraising for research, as well as a wide range of initiatives where our fundraising activities need a strong contribution from the research team
- With fundraising colleagues, ensure that we offer potential donors a compelling case for their support; this will also include supporting effective donor relations and a broader internal collaboration around marketing Action for M.E.'s research programme
- Ensure that developments in science related to ME are well communicated to our internal and external stakeholders and often to people affected by ME.
- To represent Action for ME internally, nationally and internationally on matters related to the Charity's research strategy and research programme, including acting as a spokesperson for the Charity.
- Ensure excellent working relationships with the ME scientific community, nationally and internationally.
- To identify and develop collaborative relations with governmental and non-governmental organisations, donors, Trusts and other key stakeholders (including our partner ME organisations) to raise the profile of ME and to lever additional funding to support the Charity's research strategy

### **Other duties**

- To operate as part of the Senior Leadership Team, providing support and cover for colleagues where necessary
- To positively promote the work and activities of Action for M.E. at all times and act as advocate for the Charity and its work
- To undertake any other reasonable activity in line with the responsibilities of the post as requested by the Chief Executive or the Board

## **Person specification**

### **Qualifications**

Research qualification (at least to PhD level) or significant demonstrable experience in a research-related role

### **Experience and knowledge**

- Evidence of continuous professional development.

- A successful track record in the funding, management and evaluation of complex, multi-disciplinary research programmes •
- Demonstrable experience of building successful partnerships with medical research organisations and other key stakeholders
- A proven track record of success in leading and managing a team working with complexity, to achieve high quality results to deadlines
- Experience of working in a senior team to develop, communicate and implement strategy and/or business plan
- Proven planning, programme and project management experience to control effective use of resources
- Demonstrable experience of applying effective problem-solving techniques when the situation demands
- Experience of financial and budgetary management
- A good understanding of ME science and the health research environment
- A clear understanding of a range of research methodologies
- An understanding of M.E./CFS, the impact on people affected by it and associated current political, health, policy and social issues

### **Skills and behaviours**

- Demonstrable skills in analytical and strategic thinking with the flexibility and ability to develop innovative solutions to complex problems
- The ability to drive and embed lasting change
- The ability to focus on impact and achieve outstanding results in a team environment
- Demonstrable commitment to collaborative teamwork and leadership
- Demonstrable commitment to inclusive working, ensuring equality and valuing diversity
- Exceptional interpersonal skills, and able to influence/persuade a wide range of stakeholders
- Excellent written, verbal and interpersonal communication skills, with the ability to communicate effectively in a wide range of media and to diverse audiences
- Ability to work methodically, managing and prioritising a varied workload
- Ability to use own initiative, work independently and to work well in a team
- Proven ability to develop systems, maintaining records and meeting policy and procedure requirements
- Flexible and adaptable approach
- Strong MS Office skills including Excel proficiency and ability to use databases and web-related programmes and software

### **Attitudes and values**

- Perseverance
- Enthusiasm
- Integrity
- Openness
- Compassionate
- Entrepreneurial
- Courageous
- Resilient

**Key competencies**

- Effective communicator
- Results driven
- Attention to detail

**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**

Employee contracts have one-months' notice, three-months' for senior roles, after the completion of probation period.

**2. Annual leave**

Employee's holiday entitlement is 7.6 weeks which is made up of 30 days annual leave plus the 8 statutory Bank and Public holidays (pro rata for part time staff).

**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**

We provide a fully flexible working environment where you can work whenever you want, wherever you want and however you want as long as you work within six guiding principles developed by our team. We will work with you to establish a good working pattern that suits you and us.



## Application timetable

Deadline for applications	5:00 pm Wednesday 13 April 2022
Short list meeting	Thursday 14 April 2022
Interviews (to be held over Zoom)	Monday 25 April 2022

## How to apply

To apply, please follow the below link to our application form via Google Forms:  
<https://forms.gle/NVKPj7xoCvxJxxCm7>

For more information, or to submit an application, please contact our recruitment team at Action for M.E., 42 Temple Street, Keynsham BS31 1EH. Tel: 0117 927 9551. Email: [recruitment@actionforme.org.uk](mailto: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 #yearsinslockdown 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.*