

Action for ME Philanthropy Manager Application Pack



Thank you for considering joining Action for ME

Myalgic Encephalomyelitis (ME) has been neglected and stigmatised for decades. It affects hundreds of thousands of adults and children in the UK alone, but the continued lack of investment means there is no cure and no effective treatments.

For the first time there is an increased awareness of post viral illness because of the Covid -19 pandemic. After decades of neglect this offers Action for ME an opportunity to accelerate our work for people with ME in a way we have never been able to do before.

The life-changing symptoms experienced by people with ME are being mirrored by more than half of those with long Covid. This could mean around 1.3m people are living with ME or ME-like symptoms in the UK.

We have identified areas where there is a critical lack of understanding and a severe unmet need and we have taken the decision to make a significantly increased investment in our work; to accelerate the ME research agenda; to increase the support in the healthcare and advocacy services we offer; and to do all we can to ensure the government address the neglect and health inequity faced by people with ME

Our 2022 – 2027 strategy Shaping our future together sets out our ambition to end the ignorance, injustice and neglect of children and adults with ME. By working together with the ME community and focusing on the most urgent and important challenges, we will accelerate change for people with ME on a greater scale than has been known before.

We have a talented and committed team at Action for ME where we encourage collaboration and support development and growth. I am delighted that you are considering this role, and I hope this pack shows you the part that you can play in improving the lives of everyone affected by ME.



Sonya Chowdhury
Chief Executive

"I cannot even begin to imagine what this experience would have been like without Action for ME. I know for certain I would have suffered a great deal more and almost certainly become more ill." – Information & Support service user

Action with impact

We believe that change won't just happen; it must be made.

That's why action and impact are at the heart of everything we do.

Whether that's helping people today with support, information, or care. Or working towards securing future change through our research and campaigning work.

The intent of everything we do is to pursue positive impact for the lives, rights, and futures of people affected by ME.

About us

Action for ME is the only charity in the UK providing support, including healthcare, to people of all ages affected by ME.

The charity was founded by Sue Finlay in 1987 and since then has been taking holistic approach so we can make an impact on multiple fronts - from amplifying the voices of people affected by ME in Government and leading on breakthrough research, to providing "lifeline" support and unique healthcare services on a daily basis.

Myalgic Encephalomyelitis (ME), sometimes referred to and diagnosed as Chronic Fatigue Syndrome (CFS), is a chronic, fluctuating disease, causing symptoms such as post-exertional malaise (PEM), sleep problems, problems with thinking and memory (brain fog), pain and crushing fatigue.

There are an estimated 1.3 million people living with ME or ME-like

symptoms, including PEM, in the UK alone.

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

Our vision

A world without ME

Our mission

Our mission is to improve the lives of people affected by ME. Better meeting their needs today while taking action to secure change for tomorrow.

Our 2022 – 2027 strategy, 'Shaping our future together, has been developed in partnership with children, young people and adults with ME, their loved ones and carers, and others who share our values and ambitions.

This has included learning from the services and support we provide, our surveys and consultations, workshops and discussion groups, and from wider engagement with the ME community.

You have all been absolutely amazing and I am very grateful for this organisation. I felt lost and alone and very confused when I first reached out for advice. I had two phone calls which were so, so helpful, I felt listened to and valued. –
Healthcare Services user

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 behaviours that we value in each other and underpin our whole approach and culture.

Collaboration

We will work collaboratively and inclusively with others to take action and achieve change.

Empathy

Most of our Trustees, and many of our staff team, have direct experience of ME themselves. Our collective, deep-rooted empathy is at the heart of our work.

Equity

We believe that everyone deserves fair and just access to resources, services, and opportunities. We are committed to identifying and addressing barriers that contribute to inequalities experienced by people affected by ME.

Our strategy

People with ME are at the heart of everything we do.

In our 2022 – 2027 strategy, we set out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with ME

Underpinning each ambition is our focus on ensuring we reach underserved communities, so they have better access to healthcare, information and services.

1. The lives of people with ME are improved by effective access to the information, support and advocacy they need.
2. The health of people with ME is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence guideline for ME being effectively implemented across NHS services.
3. Increased funding for high-quality research by more researchers leads to effective treatments for ME
4. The UK Government establishes and leads a national strategy for ME

You can read about the difference our work makes to people living with ME in our [annual report and accounts 2023 to 2024](#).

Our people

President

Clare Francis MBE

Vice President

Martin Arber

Patrons

- Lord David Puttnam CBE
- Lord Melvyn Bragg
- Julie Christie
- Alan Cook CBE
- Sarah Dorin
- Philip Mould OBE

Chair of Board of Trustees

Roger Siddle

Board of Trustees

- Jonathan Manuel
- Shaun De Boo
- Sue Hardy
- David Leigh
- Julianne Devine
- Philip Courtney
- Dr Nirmala Santiapillai
- Jeff Banks
- Wendy Lippmann
- Ros Boyle
- Eleanor Bulmer

We are an organisation led by people affected by ME, for people affected by ME. We aim to have a minimum of 51% of our Trustees who have, or have had, ME themselves. Our Trustees are unpaid and meet at least four times a year and many sit on one of our four sub-committees.

Our Team

We have a staff team of just under 40, many working part-time, and approximately 70 volunteers who support our work in a number of different ways. Our head office is in Bristol and we have members of the team located across the UK, including Scotland, working remotely.

Our Services

We provide free Information and Support, Advocacy and Family Support services for adults, children and young people with ME, and their loved ones.

While our Information, Support and Advocacy team does not recommend any specific treatments or management approaches, our Healthcare Services team works with individual patients to offer personalised advice, care and support.

We are not able to offer specialist legal, employment or medical advice, or specialist mental health support; instead, we signpost to specialist organisations that do.

Our Healthcare Services clinical team includes a doctor, physiotherapists, counsellors and multi-faith chaplains, offering individually tailored whole-person care. We are a small-scale healthcare service provider and do not have the complexity that the NHS and other larger providers have. We also offer a free children and young people's counselling service.

Our Resources and Peer Support

We have lots of information and support on all aspects of living with ME. Our booklets and factsheets are available for free online, or we can be sent by post or email, on topics including but not limited to:

- symptom management and accessing health services
- welfare benefits processes, rights and entitlements
- accessing social care
- liaising with your child's school
- getting reasonable adjustments at work.

Our peer-support forums for adults with ME and 18s and under with ME are free to join and users tell us they feel better supported, and less isolated.

Job Description

Job title	Philanthropy Manager
Responsible to	Director of Fundraising & Development
Salary	£49,500 - £54,075 per annum (dependent on experience)
Hours of work	Full time (35 hours per week) We consider flexible working requests including 4 day weeks for full time roles. This role is not suitable for job share.
Annual leave	30 days with 8 additional Bank Holidays
Office Base	Remote - location is flexible with option to be home based anywhere in the UK. Hybrid/office based also available (head office is in Bristol)

Job purpose

At Action for ME, we believe that change won't just happen; it must be made. That's why action and impact are at the heart of everything we do. Whether that's helping people today with support, information or care. Or working towards securing future change through our research and campaigning work.

You will be joining us at a time that holds the greatest potential for fundraising in our history, following the launch of the UK Government's Delivery Plan for ME and initial findings of the DecodeME genetics study (co-led by Action for ME) in Summer 2025.

Working closely with the CEO, alongside managing a portfolio of donors and prospects ensuring excellent stewardship, you will support our Breakthrough-ME Group (a group of high net worth and highly networked individuals). There is an established level of support from major donors at Action for ME so this is a role that will require exceptional relationship management to retain our current valued supporters while growing this crucial area of fundraising.

This would be an ideal role for an experienced philanthropy professional seeking to work for a small but ambitious charity, helping us to achieve our mission to improve the lives of all people affected by ME – better meeting their needs today while taking action to secure change for tomorrow.

Key duties

Major Donor Fundraising

- Successfully develop and implement the philanthropy strategy to secure and maximise funds from high value individuals for Action for ME achieving annual income of £250k+
- Set plans and budgets which will deliver income through major gift fundraising and philanthropic giving through family trusts and foundations, including quarterly forecasting.
- Manage a portfolio of prospects and donors at the £5k to £100k level, to develop and maintain strong and long-standing partnerships
- Work closely with the Director of Fundraising and Development and other colleagues to ensure that plans and activities for fundraising from high value individuals are integrated into the overall fundraising strategy and plan for significant growth.
- Be responsible for our Breakthrough-ME Group with high quality proposition development. Contribution to Group fundraising activities with a specific focus on ensuring their networks support pipeline growth for future fundraising.
- Lead the delivery of our biennial fundraising gala dinner, maximising income and new opportunities from attendees.
- Develop engaging and inspiring opportunities to steward and cultivate support creating a calendar of activities including events, presentations, approaches, networking and meetings.
- Utilise the CRM database (Raisers Edge) to provide the data required to strategise your approach to philanthropy, monitor progress and provide a high-quality donor experience.
- Ensure utilisation of insight & data, producing management information data to inform planning and strategy development.
- With the Director of Fundraising & Development, create inspiring cases for support and resulting propositions with clear budgets and outcomes.
- Create adequate systems and processes to support the major donor programme.
- Undertake and manage research into prospects and major donors, preparing for approaches and presentations and briefing senior leadership and trustees for donor meetings and events.
- Develop and maintain relationships with donors, a wide range of staff and volunteers from trustee level down.
- Provide regular feedback and internal reporting to line management.
- Work with other fundraisers to ensure that all fundraising opportunities and leads are followed up – particularly in corporate, community and trust fundraising.
- Work with Trustees, the Chief Executive and members of the Leadership Team to develop relationships with major donors.
- Self-administrate including managing your own diary and meetings, keeping accurate and up to date records of activity
- Occasional travel to London, Bristol & events

Other duties

- To positively promote the work and activities of Action for M.E. at all times.
- To contribute to the team's overall, ongoing and annual planning and budgeting.
- To undertake any other reasonable activity in line with the responsibilities of the post as requested by the Director of Fundraising and Development, Chief Executive or any other senior Action for ME management.
- Act as an advocate for the Charity and its work.
- To work in accordance with Action for ME's values of collaboration, equity and empathy.

Person specification

Experience and knowledge

- Hold three to five years' proven experience in generating income from major gifts
- Demonstrable success in securing major gifts (£10k+) and delivering a successful major donor programme
- Demonstrable skills in writing effective and inspiring propositions and cases for support
- Proven track record in high level effective stewardship of donors, funders and prospects or transferable skills.
- Experience of using a CRM database to build a measurable pipeline of major donors and prospects or similar.
- Proven of developing varied methods of donor engagement including events, donor clubs or patron schemes or similar.
- Strong understanding of data protection and fundraising regulations
- Experience of servicing a fundraising board/campaign board (desirable)

Skills and Behaviours

- Excellent communication, engagement and interpersonal skills
- Strong organisational skills and able to self-administrate
- Ability to travel and work flexibly including occasional evenings and weekends
- An understanding of M.E./CFS, the impact on people affected by it and associated current political, health, policy and social issues (desirable)

Attitudes and values

- Enthusiasm
- Integrity
- Resilient
- Donor-centric

Key competencies

- Effective communicator
- Results driven

Terms and conditions

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

1. Probation

All posts are subject to three months' probation. During this probationary period, either party may give the other one week's notice in writing to terminate the employment. After successful completion of the probationary period, the notice stated on your contract of employment will apply.

2. Annual leave

The holiday year runs from 1 April to 31 March. In each holiday year in addition to bank and statutory holidays the holiday entitlement for a full-time employee is 30 days (includes 3-4 days to be taken at Christmas as directed when the office is shut).

3. Pension scheme

Action for ME operates a group pension scheme on an auto-enrolment basis. All employees will join the scheme on the completion of three month's service unless they choose to opt-out. Action for ME will pay a pension contribution which is currently 4% of salary. Action for ME will not pay into a personal pension scheme.

4. Salary payment

Salaries are paid on the 24th day of each month, by direct credit transfer into a bank or building society.

5. Flexibility & Wellbeing

This post may require working outside of normal office hours and travel to attend meetings and events within the UK, including occasional overnight stays. We provide access to an Employment Assistance Programme and regular virtual coffee catch ups with colleagues across the organisation.

We offer a flexible working model, in accordance with six working principles developed by the team:

a) Your working hours/practices do not disadvantage others.

This means:

- Your working hours must not impact negatively on the people we are here to serve. The core hours of client-facing services must be delivered and boundaries with/for all clients must be maintained.
- Safeguarding and wellbeing remain a priority. You will reasonably be able to access management support when needed in an emergency

and/or safeguarding concerns exist. This may include a 'matrix management' approach to provision.

- Your working hours must not disadvantage colleagues. You need to be available for colleagues/meetings in 'normal working hours' with a good percentage of cross-over time.
- Each team must manage its own outgoing post. Your line manager can provide details of the arrangement for your team.
- Flexibility all round. We all need to work flexibly to achieve the best results, and this will require compromise.
- Good stewardship is maintained. We must continue to be cost effective and efficient, ensuring we deliver value for money and that quality delivery is maintained. We will need to ensure all legal and regulatory requirements continue to be met.
- If you wish to compress your hours, this is limited to working 5 days in 4 for full time employees and no more than 8.75 hours per day (excluding lunch break) for part time employees

Work where you work best.

You will be supported to work in the location where you can use your talents most effectively and contribute to your team and Action for ME This means you will be supported to work in the office, at home, or a combination of the two in a pattern to be agreed on an individual basis with managers and their team members.

There are three broad interpretations of this principle:

- An office is the right place to work for some people. If this is you, and you will be based in the office a majority of your time, (4 days/week or more if full time or 90%+ of contracted time if part-time) you will require a desk and will be provided with one.
- Home is the right place to work for some people. If this is you, and you will be based at home the majority of your time, (4 days/week or more if full time or 90%+ of contracted time if part-time) you will be provided with suitable support to work from home full-time and will use hot desks when in the office.
- Some people need a mix of both home and office. If this is you, and you will be based either 2 days at home/3 days in the office or vice versa model (full time workers) you will be provided with suitable support to work from home and will use hot desks when in the office.

b) Location doesn't matter.

This means we recruit and retain the best people wherever they live in the UK. All jobs will be advertised as home/flexible/office-based to attract the widest pool of talent unless funding/role requirements dictate otherwise.

- People can change their location. Staff who are currently home-based may wish to become office-based and vice versa. So long as due notice is given, and budgets and existing office contracts allow, a change in preference will be accommodated.
- 'Home' doesn't have to mean 'home' - if you want to temporarily work somewhere else. If you have a secure internet connection suitable for professional meetings remotely, you can work from your house, a

family members house, another office or suitable environment you can still work. This means even whilst accompanying family or friends whilst they are on holiday and you are working.

c) Technology is our friend.

This means:

- Everyone will be equipped to work from home or other location outside the office if required. This means we could cope with future lockdowns or business interruption at short notice if needed.
- We don't wait until people are physically together to hold meetings. People should be able to meet remotely, in person, or a mixture of both at any time. This means we will have suitable video conferencing facilities on site in Bristol to support this.
- Outlook calendars are always up to date so that we know where colleagues are working and when they are, and aren't, available for work-related discussions.

d) Physically being with people and teams matters.

This means, regardless of whether you are majority office, home or mixed office and home based all staff will commit to the following (unless reasonable adjustments are required):

- Being able to travel to and meet in Bristol for team meetings no less than twice a year (this may be whole team meetings or individual team meetings).
- Being able to travel and hold 121's in person with your manager at least twice a year. This may be in the office, or it may be in an agreed location out of the office.
- Line managers to meet face-to-face with new colleagues at least once in the first 3 months.
- Annual appraisals always taking place in person.
- Committing to at least one whole team event together each year as a whole Action for ME team (as part of an Away Day).
- Making an effort to find out about other teams and sharing with them what is happening in yours.

e) Personal leadership is essential

This means:

- If things aren't working/you spot issues, you take action to redress them at the earliest possible stage; this may include sharing concerns immediately with a manager or working with others to identify a solution.
- Individual performance levels must be maintained. Any reduction in performance will be addressed immediately, in accordance with policy and procedures.

6. Colleague Benefits

A summary of the benefits offered to colleagues is as follows:

- Flexible Working: Full flexibility to work where and when you want, based on team-developed principles.

- Enhanced Pension Scheme: A 4% employer contribution, exceeding the statutory minimum.
- Generous Annual Leave: 30 days plus bank holidays
- Employee Assistance Programme (EAP): Access to BACP-accredited counselling and support services for staff and their families.
- Disability-Related Absence Pay: Currently being piloted.
- Enhanced Sick Pay: Improved for better employee support.
- Performance-Related Pay: Annual awards determined by the Board of Trustees.
- Compassionate Leave: Three days standard, with up to 10 days at the CEO's discretion.
- Additional Time Off: For dependant emergencies and discretionary unpaid leave.
- Eye Test Contribution: £30 every two years towards eye care.
- Cycle to Work Scheme: Promoting sustainable and healthy commuting.
- Wellbeing Session: Focus determined by staff. Budget and time off for attendance provided - as well as fortnightly online coffee mornings.
- Study Assistance Policy: Support for learning, development, and career growth through training and mentoring.
- Career Breaks: Opportunities for extended career development breaks.

How to apply:

Applications should be submitted via our recruitment website here:

<https://actionforme.recruitee.com/o/philanthropy-manager>

Along with your CV your cover letter should, in no more than two A4 pages, explain your reason(s) for applying for this role and how you fit **all** aspects of the person specification set out above.

Strong applicants will list each person specification bullet point related to experience, skills and behaviours and provide evidence of how they meet each of these criteria.

We are proud to be a member of the Disability Confident scheme and offer a guaranteed interview to applicants who can clearly demonstrate, via their written application, that they meet **all** essential criteria set out in the person specification.

Should you have any questions about the role, or require any reasonable adjustments to the recruitment process, please don't hesitate to contact colleagues on recruitment@actionforme.org.uk

Please note that any applications sent directly to any Action for ME mailbox will not be considered.

Key Dates:

Deadline for applications	22 nd September (midday)
Shortlisting; shortlisted candidates will be invited to interview	24 th September
First interview (online)	3 rd October
Online meeting with Chair of Trustees and mock donor call	w/b 6 th October Call with the Chair will take place on 7 th October
Final interview (in person in Bristol)	15 th or 22 nd October

How to apply

To apply, please follow the below link to our application form via Recrutee:

<https://actionforme.recrutee.com/o/philanthropy-manager>

For more information please contact Lizzie Packham at Action for ME, Unit 2.2 Streamline, 436-441 Paintworks, Bristol, BS4 3AS. 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 ME; 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 ME 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 ME CEO Sonya Chowdhury at a webinar for DecodeME, the world's largest ME 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.