



Action for M.E. Trustees' report

2022 – 2023





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 been ill for more than 30 years with M.E. As one in four of those with the illness who are severely affected, she is only able to manage basic self-care.

"It has affected everything to the point where I don't have any routine or structure. My day is spent 24/7 in bed, managing just the basics of going to the loo and hopefully getting some food when health and energy allows, which can be different or not at all each day. Everything is dictated by a constant self-monitoring of what I can manage or not rather, than the clock."

As a way of managing her energy, and to combat brain fog, Joanna keeps a diary of every email, phone call, visit and letter, noting actions she needs to take or responses she's waiting for. This also helps with the isolation that affects so many with M.E.

"Not having the emotional support desperately needed to help mentally deal with all the loss and limitations it brings is an additional burden of M.E. But I know it's ok to feel emotions during challenging times. I often write it all down and then become my own support system to build myself back up, remembering what I have already overcome and using self-talk to be my own best friend. I use my iPad for all social and support contact, using forums and websites that offer online help and crisis services if needed."

Like many people with M.E., Joanna has often found herself in the position of having to explain the impact of the

condition – and in some cases the fact that it even exists – to those around her.

"Before the illness was more understood, I have had many encounters that cause more harm than good. The stress of just having to justify myself as a legitimate patient is exhausting. Instead of it being the patient's responsibility to reach up to the medical community to become visible and educate them on our needs while so ill, I wish they could reach down and see what our lives are like, so they can take on the burden of initiating the changes that are needed.

These changes would be based on education and awareness of the illness, but also basic human kindness; care and respect that ensures interactions with them do not cause more distress, or the self-blame and judgement that are so common."

In seeking out this holistic support, 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."

Action for M.E. is here for everyone affected by M.E. For information and support call us on 0117 927 9551 or email questions@actionforme.org.uk

We are incredibly thankful to Joanna for the time, energy, and willingness it took for her to share her story. For more information on how Action for M.E. can support you, or a family member affected by M.E., please contact us on 0117 927 9551 or questions@actionforme.org.uk

Chief Executive's message

In 2022 – 2023, we continued our important work supporting children and adults with M.E., and their families, alongside professionals working with them.

Like many others, we have been saddened to see around 50% of people diagnosed with Long COVID experience symptoms that directly mirror M.E. Our mission is to support people now while seeking to secure change for the future, but to see the numbers dramatically increase in this way has been challenging and our services have been in greater demand than ever.

People affected by M.E. exchanged nearly 3,000 calls, emails, texts, and direct messages on social media with our Information and Support service, with 99% reporting they were either satisfied or very satisfied with the service they received.

I am also delighted to say that in their first full year of operation since our merger with the M.E. Trust, our holistic Healthcare Services have provided over 1,200 consultations to people with M.E. – many who self-reported as severely affected – with tailored, patient-focused support from our dedicated doctors, physios, counsellors, and multi-faith chaplains. Despite our successes, we know demand still outweighs the level of support we are currently able to offer. We hope that further recruitment into our Healthcare Services will reduce current waiting lists.

We continue to remain committed to driving high-quality research in the field of M.E. and in, May 2022, we concluded the work on the M.E./CFS Priority Setting Partnership (PSP) which was led by people with M.E./CFS, their carers and clinicians, and facilitated by Action for M.E., with support from the James Lind Alliance. After 5,300 research ideas were submitted, a series of workshops

established the Top 10+ priorities which were published on World ME Day, 12 May 2022.

Furthermore, we maintained a core focus on delivering the DecodeME study, which we are co-leading with the University of Edinburgh, and a very committed steering group of people with lived experience of M.E./CFS.

We opened recruitment in September 2022, inviting people to complete a questionnaire which has now created the world's largest dataset on people with M.E./CFS. Our first analysis, undertaken on the data provided by the first 17,000 people who completed the questionnaire, is about to be published.

Since then, by August 2023, we achieved 19,000 invites to provide DNA, nearing our 20,000 target.

Another pillar of work which has been given an increased level of focus is our work in supporting and shaping the UK Government's National Strategy for M.E. and we are pleased that the Rt Hon Sajid Javid MP, then Health and Social Care Secretary, welcomed the aforementioned PSP priorities and declared that more must be done for people with M.E./CFS.

He also announced his plan to Co-Chair a roundtable with the Department's Chief Scientific Adviser to set out next steps and, in his ministerial announcement, stated the Government's intention to develop a cross-Government Delivery Plan on ME/CFS for England, aligning with other devolved nations as appropriate.

Thank you for taking action with us to improve lives and shape the future for people with M.E.



Sonya Chowdhury
Chief Executive
Action for M.E.

"Action for M.E. is always the first place I go to get help or information. I have been helped many times over the years and I always get a quick response." – Dave

Chair's message

The world has not become any easier for people with M.E. in the UK since I wrote my statement last year.

We emerged from lockdowns and learning to live with COVID-19, only to be faced with a cost-of-living crisis. This has undoubtedly impacted those who need the most support, including people with long-term health conditions like M.E.

The demand for our services and support has correspondingly increased. As we build on the legs of our strategy, outlined last year, (of which you will read more in the rest of this report) we have therefore had to prioritise carefully what we can achieve with our available resources.

Our colleagues providing information, support, and advocacy found that the needs of some of those we support have become increasingly complex and, as a result, we have needed to provide more time and more support. At times we have therefore had to close our waiting lists for our Advocacy Service, which was not a decision we took lightly. We are now reviewing how we can best reach and support people with the income we have available.

From April 2022 to March 2023, our first full financial year post-merge with the ME Trust, we provided Holistic healthcare support to over 790 people. We are in the process of adding new doctors and other healthcare professionals to the team

– with very high demand we hope to be able to bring waiting lists down soon.

In her statement, Sonya outlined a variety of activities on the research leg of our strategy and it is pleasing to see strong progress being made. This is an area of increased focus for us, and with the charity's involvement in the Priority Setting Partnership, DecodeME, and researchers we fund directly, we feel we are having a demonstrable impact.

Similarly, it has also been gratifying to see the announcement of the consultation on the Interim Delivery Plan on ME/CFS announced in August 2023 – although there is still much to be done, we can hope this is the start of a change in attitudes towards, and support for, people with M.E. The charity has played a significant role in helping input to, and shaping, the overall Plan.

Thanks to continued, unwavering support from you – our donors, funders, fundraisers, supporters, volunteers, and the rest of the M.E. community – our income for the year reached £1.1 million.

This includes another successful Big Give Christmas Challenge fundraising campaign, raising £155,610.

Together with the exceptional legacy received last year, we had a more solid base on which to try and expand

our efforts, but increasing our income remains a priority – as noted earlier, demand for our support outstrips our resources and we continue to need to balance what we can deliver with the income we achieve.

I continue to be proud of the work my colleagues here at Action for M.E. have done to help so many of the recent, substantive developments for people with M.E., as well as improve the lives of the people we support directly.

But none of this is possible without our supporters and donors – thank you for the part you have all played.



Roger Siddle
Chair of Board of Trustees
Action for M.E.

"I'm so glad I decided to reach out. I'm so thankful for the wealth of support and information which has given me some confidence and factual information to enable my diagnosis. Thank you so much for all the time and effort spent assisting people like myself, who didn't know where to turn to find accurate knowledge, this service has helped me gain the tools I felt I needed to be able to continue my quest to be taken seriously." – Fiona

Contents

Chief Executive's message	4
Chair's message	5
Our year in numbers	7
The lives of people with M.E. are improved by effective access to the information, support and advocacy they need	8-9
The health of people with M.E. is improved via access to our holistic Healthcare Services	10-11
Increased funding for high-quality research by more researchers leads to effective treatments for M.E.	12-13
The UK Government establishes and leads a National Strategy for M.E.	14
A special thank you	15
Our finances	16-17
Our people, structure and governance	18-19
Financial review	20-21
Independent Auditor's report to the Members and Trustees of Action for M.E.	22-24
Statement of financial activities	25
Balance sheet	26
Cash flow statement	27
Notes to the accounts	28-38
Legal and administrative details	39

Our year in numbers

*"Like sight of harbour
in a storm." – Mary*

**Almost
3,000 hours**

spent supporting people affected
by M.E. of all ages across our
Information, Support and
Advocacy Services

75%

of attendees of our Breaking
Isolation workshops, funded by
BBC Children in Need, said they
**felt reduced loneliness as
a result.**

*"The community I've
found with Action for
M.E. has been
wonderful and helped
me to feel less alone."*



**£155,610
raised**

in our 6th Big Give
Christmas Challenge



10,000+

DecodeME sign ups in the
first week since launch

Our newly integrated, holistic
Healthcare Services provided

**over 1,200
consultations**

in their first full year of operation

*"I am so grateful for this prompt, kind-hearted
and empathic service. I feel more hopeful
and empowered." – Fionnuala*

87%

of people reported feeling less
isolated after accessing our
Information and Support Service



Episodes of our *Learn About M.E.*
podcast have been downloaded

1,577 times

across all major streaming sites

A total of

74.8m people

had the chance to see our
interviews, letters and stories in
newspapers and magazines



of parents felt in a stronger
position to support their child
after accessing our Family
Support Service



Our vital online resources
were downloaded

36 times

every working day

*"Just very lovely, very
understanding and
listened to me.
Invaluable service."*

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

People with M.E. who contact us often tell us it's the first time they have felt accepted and believed. Louise had been living with Long COVID for nine months when she called our Information & Support Service, worried that her GP surgery were not listening to her concerns about additional emerging symptoms.

"It was just really nice talking to someone who understood what it's like living with a debilitating health condition without me having to explain myself or being dismissed. I got more useful resources and information from one call than I have from my GP surgery in over a year." – Louise

After contacting our Information and Support Service:

99% were very satisfied or satisfied with the service they received

87% felt less isolated

89% reported increased understanding of their rights and options



People affected by M.E. exchanged **nearly 3,000** calls, emails, texts and direct messages on social media with our Information & Support Service.

Tackling isolation

Sharing experiences with others who understand M.E. is invaluable. Our popular M.E. Friends Online forum now has more than 5,000 registered users.

"I get a lot of support, advice, laughter and friendship from the forum." – Hazel (Eskdale23)

For those who aren't able to use screens or access online support because of its impact on their symptoms, our membership magazine, *InterAction*, is often described as a lifeline. People with M.E. use it to share their tips, ideas and experiences, and also catch up on essential M.E. news, research and updates.



To address the needs of those looking for emotional support, we launched our Listen to M.E. helpline in May, open to any adults affected by M.E., including carers.

Our fantastic, fully trained volunteers offer callers acceptance and understanding so they can talk through the things on their minds.

"This is a fantastic service to offer people. The volunteer I spoke to was very kind and caring. She took the time to listen to me which was much appreciated."

Advocacy for adults

14 adults took part in our self-advocacy workshops on employment, communicating with health professionals and Self-Directed Support in Scotland, or watched them on YouTube.

60% reported increased understanding of their rights and options.

80% said they had increased self-advocacy skills.

Over the year, 70 adults with M.E. worked one-to-one with our Advocacy service. Some accessed more than 100 hours of individual support to challenge decisions made about their care and support, and/or to produce tailored impact statements they can share to help the professionals around them better understand M.E.

Most of these clients were severely affected, and we worked at their pace to focus on agreed goals that they prioritised – for some, this meant making very gradual progress by letter and text message.

"I am grateful to you for your acumen, friendliness and understanding. You were the ONLY professional body that took me seriously." – Charlotte

Increasing demand for this service and sector-wide challenges around recruitment and retention of staff have now prompted us to undertake a full review of how we effectively offer Advocacy for adults with M.E., to ensure we can continue to be there for those who need us most.



With your support, we can be here for even more people with M.E. of all ages, sharing the resources and support they need to make informed decisions about their care, and standing alongside them to advocate for change.

Supporting families

Many of the parents who initially call Information & Support are referred onto our Family Support Service. We worked with 55 families from July to year end, supporting them to communicate more effectively with their child's school and/or doctor, better understand their family's rights and entitlements, and feel more confident to speak up for what they need.

As a result:

- 92%** reported feeling in a stronger position to support their child.
- 100%** said they were either satisfied or very satisfied with the service they received.

"I am so grateful for the Family Support Officer's support. She has been fantastic and has helped me to access support from my daughters school and GP. I wasn't being listened to, [and] her letters spelt out what each of them should be putting in place for me daughter. I have benefited massively in having someone to speak to who understands." – Jen

Children and Young People

Many of the young people with M.E. whose parents we support access our range of specialist services designed just for them.

Each month, hundreds read stories and poems by their peers in *Cheers* e-magazine, edited by Helen, a dedicated volunteer. Many share their experiences by posting in our friendly online forum, moderated by volunteers Tiggy and Emily.

"When I was at my most unwell the forum made me feel less alone and less 'odd' than I felt with my peers, and the older or more experienced members gave great advice for school and mental health. I still read Cheers regularly and have submitted pictures of my crafts, and it is a cheery email of happy things that has been the highlight of my crashes."

Over the year, some worked one-on-one with our Children and Young People's Advocate. In collaboration, they developed an Advocacy Agreement that sets out what actions each will take to achieve the young person's goal, entirely led by their needs, wants and wishes.



More than 20 young people took part in our Breaking Isolation workshops project, generously funded by BBC Children in Need, and shaped and facilitated our amazing young Steering Group.

Together, they shared experiences and took part in craft activities, helping them feel better connected.

"The peer facilitators were all really friendly! I like that it was a no pressure environment and even though I didn't participate that much, I still felt part of the group."

Some of those who took part wanted a resource to help their peers, friends, family, doctors and schools understand what having M.E./CFS means to them, resulting in our brilliant *Explaining M.E./CFS* factsheet, developed entirely by young people with M.E.

The health of people with M.E. is improved via access to our holistic Healthcare Services



Holistic healthcare

In a healthcare landscape where the intricacies of M.E. are often overlooked by professionals and many basic care needs fail to be met, we understand how difficult and frustrating it can be for people with M.E. to secure the support they need. In April 2022, we successfully completed a merger with the ME Trust and launched Action for M.E.'s Healthcare Services, offering holistic, tailored and patient-led support to young people and adults with M.E. in the UK.

Our Healthcare Services provided over 1,200 doctor, physio, counselling and chaplaincy consultations in their first full year of operation, with:

- 95%** reporting they would recommend our service to others.
- 100%** reporting feeling listened to and understood.
- 100%** reporting they felt involved in the planning of their treatment.

Doctor service

Our doctors provide an individual, clinical assessment of the biological aspects of the whole person. Reviewing the information provided regarding a patient's medical history, medication, investigation and interventions tried elsewhere, they give their medical opinion.

Given the challenges that many people with M.E. face when securing appropriate healthcare for their condition, demand for our doctors' service has been particularly high, with a long waiting list forming as a result.

In order to reduce this and ensure that patients can access the care they need, when they need it, we have been working to recruit more doctors into our organisation and are pleased to say that, at the time of writing, we are in the process of welcoming in a number of new doctors.

"Thank you so much for the appointment with one of your doctors. I finally feel like I've been heard. The doctor really listened and, for the first time in years, I feel as though there is a light at the end of the tunnel. Their gentle and kind manner took all the stress out of the appointment. I am just so, so grateful."

Counselling

Our counselling service worked with over 400 patients across the year, providing supporting and therapeutic sessions that place an emphasis on listening and offering emotional and practical support.

Of those who responded to our annual feedback survey:

- 83%** reported feeling less isolated as a result of talking with their counsellor.
- 83%** reported that speaking with their counsellor had a positive impact on their emotional health.
- 88%** reported feeling more support and/or hopeful after their sessions.

"Thank you so much. I'm extremely grateful for the support I've received from Action for M.E. over the last two years. Please understand that, along with the counselling service, it has been life changing and I never imagined, for example, that I could be living independently. The help and advice I've received has contributed to that immensely."

Chaplaincy

Our chaplains provided over 90 consultations throughout the year, offering people with M.E. and carers, aged 18 and over, pastoral care and spiritual accompaniment, focusing on each person's wellbeing in their spiritual or faith journey. One of our experienced chaplains, Ruth, told us:

"It is a privilege to journey alongside people with M.E. Each person has a different M.E. journey. I have heard so many stories of courage, hope, determination, and creativity."

Of those who responded to our patient satisfaction survey:

100% reported feeling an increased sense of hope after speaking with one of our chaplains.

100% reported feeling less isolated.

100% reported improved levels of spiritual wellbeing.

Physiotherapy

Our physiotherapists' expertise and advice aims to help improve quality of life, supporting patients to identify their priorities and aims.

Throughout the year, the service worked with over 240 people, helping them to identify their baseline function and develop a plan to give patients a sense of control and hope.

"My physiotherapy sessions have been amazing. They were really supportive and helped me find ways to make my life easier and more manageable. I felt understood and affirmed in my sessions I would recommend physiotherapy sessions with Action for M.E."

"I've just finished an appointment with one of your Chaplains. Brilliant. Our conversation has really lifted me and I've got goals and feel that support and acknowledgement I've needed."

Bursaries

As a charity, we want to make all our Healthcare Services available to those in need without charging for them.

While we strive to make that dream a reality, our most important mission is to keep our charges low, extending our reach to as many people in need of our support as we possibly can.

In our first full year of Action for M.E.'s Healthcare Services, we awarded almost £10,000 of bursaries to help people with M.E. access the care they need.



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



DecodeME is the world's largest study investigating the causes of M.E./CFS, led in partnership by Action for M.E. and the University of Edinburgh (UofE), with a steering group of people with lived experience.

Full recruitment was launched in September 2022, with over 10,000 people signing up to take part in the study within the first week and 7,000 already having completed the DecodeME questionnaire to become a participant. At the time of writing (Aug 23), over 19,000 have also been invited to provide DNA samples.

Preliminary findings from data from the first 17,000 questionnaires is due for publication in August 2023.

If you are over 16, have a diagnosis of M.E./CFS and live in the UK you can take part now and help DecodeME: www.decode-me.org.uk

#DecodeMEMatters



Paul Duley - DecodeME Participant

"DecodeME matters to me as it's a rare opportunity, as an M.E. sufferer, to participate in a biomedical study, easily and from home. It's particularly important as it has the potential to indicate why some people get M.E. when others don't, and perhaps point to pathways for prevention and treatment."

World ME Day 2023

FULL RECRUITMENT LAUNCHED
12 September 2022
12k people signed up in the first week

Data Analysis Plan Shared online
27th March 2023

FIRST BATCH SENT TO THERMO FISHER
3 April 2023
5k samples sent to Thermo Fisher to extract genetic data

20,000 completed questionnaires
24 April 2023

10,000 DNA Participants
2 May 2023

MORE PARTICIPANTS INVITED TO DONATE DNA
26 June 2023
Criteria were broadened which allowed more participants to take part in the DNA stage of the study.

18,000 DNA Participants
25 July 2023

CLOSING RECRUITMENT
15 November 2023 (TBC)
Deadline for signing up and completing the questionnaire.

DEADLINE FOR RETURNING SPIT KITS
31 January 2024 (TBC)
Existing participants will have until this date to return their DNA samples.



Genetics Centre of Excellence

In September 2022, we launched the M.E./CFS Genetics Centre of Excellence with a research summit at the University of Edinburgh.

This partnership seeks to accelerate research to identify causes and find treatments for M.E./CFS. We aim to build a network to increase partnerships, funding and research while bringing new researchers into the field.

Through the Centre, we will also ensure that we bring together researchers in other overlapping post-viral areas to collaborate, share knowledge and build momentum.

The Centre will also provide a virtual home to a Future Leaders Network of research students working in the M.E./CFS field, and to the Clare Francis Research Fellowship, to which we expect to appoint the first ever Fellow in 2023.

In Summer 2022, Sonya Chowdhury (our CEO) and Prof Chris Ponting (UofE) ran a Summer School with the students in Edinburgh. This sparked great insight and learning, with the students having the opportunity to engage with other researchers. We also funded two internships in the US with Simmaron Research and Dr Dan Peterson.

PhD Studentships

In 2022 – 2023 we made further investment in the new generation of scientists through the co-funding of two PhD students:

- Luke Marney (Institute of Psychiatry, Psychology & Neuroscience, Kings College London) is co-funded with ME Research UK. He is working on mobile elements within DNA that may be related to a predisposition to M.E./CFS.
- Dr Inga Williams (Nuffield Dept. of Obstetrics & Gynaecology at John Radcliffe Hospital, Oxford) is co-funded with Oxford University. Inga's DPhil is focused on the role of gut bacteria in M.E./CFS.

Over the last year, we have been in discussion with other charitable trusts to develop more jointly funded studentship opportunities, alongside engaging with recognised centres of research excellence around the UK.

Not only does this enable us to increase the next generation of scientists but also provides opportunities for funding not previously available for M.E. research.

"The summer internship has instilled in me the importance of the clinical impact of research in M.E. and motivated to continue working on this important and exciting research field." **Audrey Ryback, Intern**

We're also pleased to note that Dr Josh Dibble, whose PhD at the University of Edinburgh was part-funded by Action for M.E., completed his PhD just after the year ended and has now moved onto a prestigious post-doctoral position at the Innovation Centre for Computational Health, Harvard Medical School, USA.



**James
Lind
Alliance**

Priority Setting Partnerships

ME/CFS Priority Setting Partnership (PSP)

During 2020-2022 Action for M.E. facilitated the M.E./CFS PSP, supported by the non-profit making initiative, the James Lind Alliance. This participatory process (known as 'PrioritiseME') identified the top 10+ research priorities for M.E./CFS to influence future research funding. Early this year, two research volunteers joined our research team to support a mapping exercise for new peer-reviewed publications and policy documents.

This evidence is being mapped against the PSP research priorities and underpins our decision making.

"I've found the role itself both enjoyable and interesting. I feel the work we are doing is a very worthwhile contribution to the efficacy of Action for M.E."
Research Volunteer

Priority 1

What is the biological mechanism that causes post-exertional malaise (symptoms caused or made worse by physical, mental or emotional effort, which can be delayed) in people with ME/CFS? How is this best treated and managed?

Priority 2

Which existing drugs used to treat other conditions might be useful for treating ME/CFS, such as low dose naltrexone, or drugs used to treat Postural Orthostatic Tachycardia Syndrome (POTS)?

Priority 3

How can an accurate and reliable diagnostic test be developed for ME/CFS?

Priority 4

Is ME/CFS caused by a faulty immune system? Is ME/CFS an autoimmune condition?

Priority 5

Are there different types of ME/CFS linked to different causes and how severe it becomes? Do different types of ME/CFS need different treatments or have different chances of recovery?

Priority 6

Why do some people develop ME/CFS following an infection? Is there a link with long-COVID?

Priority 7

What causes the central and peripheral nervous systems (brain, spinal cord and nerves in the body) to malfunction in people with ME/CFS? Could this understanding lead to new treatments?

Priority 8

Is there a genetic link to ME/CFS? If yes, how does this affect the risk of ME/CFS in families? Could this lead to new treatments?

Priority 9

What causes ME/CFS to become severe?

Priority 10

How are mitochondria, responsible for the body's energy production, affected in ME/CFS? Could this understanding lead to new treatments?

Priority 10+

Does poor delivery or use of oxygen within the body cause ME/CFS symptoms? If so, how is this best treated?

The UK Government establishes and leads a National Strategy for M.E.

Cross-Government National ME/CFS Delivery Plan

We are delighted to continue working with others in the M.E. field to secure commitment from the then-Health Secretary of State for Health & Social Care, Rt Hon Sajid Javed MP, for a cross-Government National ME/CFS Delivery Plan.

As part of this work, our CEO, Sonya Chowdhury, and a member of the Priority Setting Partnership (PSP) with lived experience of M.E., presented the output of the PSP at a roundtable hosted by the Secretary of State, which helped lead to the Delivery Plan.

Action for M.E. also continues to provide secretariat support for the All-Party Parliamentary Group (APPG) on M.E./CFS, including the launch of the APPG Report.



Raising Awareness

We know that in order to secure future change, we must continue to raise awareness of M.E. amongst the general public, healthcare professionals and key decision-makers.

Throughout the year, we have taken part in numerous radio and media interviews with the BBC and others, alongside featuring in a four-page profile piece for the leading charity sector publication, ThirdSector. As a result, over 74.8m people had the chance to see our interviews, letters and stories featured in newspapers and magazines.

Furthermore, our work has been mentioned in five different debates and we have participated in multiple meetings with MPs and Peers, ensuring that the voices and experiences of people affected by M.E. are heard and not forgotten.

These debates have been led by Government Ministers such as Lord Parkinson, Paul Scully MP (Minister for Small Business), and Guy Opperman MP (Minister for Pensions and Financial Inclusion, Minister for Arts).

We have also participated in a series of meetings with MPs and Peers in the House of Lords, leading to M.E.

being highlighted through questions raised in both houses and ensuring that the voices of those affected by the condition are heard.

We met with Debbie Abrahams MP and continue to engage with Carol Monaghan MP through the APPG.

We continued to raise awareness through the publication of a Freedom of Information report to explore how the 2021 NICE Guideline has been implemented and to gain a better understanding of the current state of M.E./CFS services in England. The report's findings serve as a basis for further advocacy and media work, and generated discussion on M.E. across clinical and political circles.

Furthermore, we have also engaged with politicians in Scotland, holding productive meetings with Jenni Minto MSP and Beatrice Wishart MSP. Jenni Minto was subsequently promoted to Minister for Public Health, and she is visiting the DecodeME study in this capacity.

We are excited to continue building on these successes and advocate for people with M.E. in the coming year.

A special thank you

We simply would not be able to do what we do without your support and so this section of the report is dedicated to you – our donors, funders, fundraisers, supporters and volunteers.

BBC Children in Need

We would like to say a special thank you to BBC Children in Need, without whom we wouldn't have had the opportunity to work with the brilliant young people who took part in our Breaking Isolation workshops.

Tea Party for M.E.

We are once again incredibly grateful to Anna Redshaw for raising over £30,000 for M.E. charities across the world, with more than £7,500 going to Action for M.E. Anna's dedication to raising funds for people with M.E. helps to ensure access to the necessary care and support they so desperately need.

Our 2022 Marathon runners

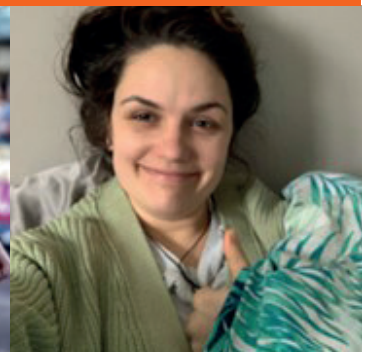
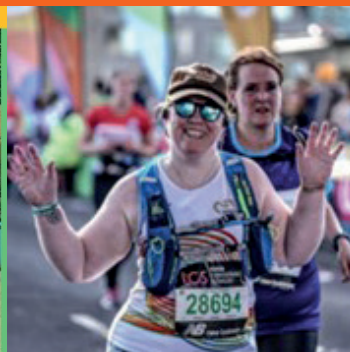
A huge thank you to all those who took part in the Edinburgh and London Marathons, raising over £36,000 in support of our work.

Our volunteers

We also want to thank all our dedicated volunteers who help to proof-read our *InterAction* magazine, moderate our forums, write Birthday and Christmas cards, support the running of our Listen to M.E. service, and much more.

Partnering organisations

Finally, a thank you to all the organisations we work closely with to support people with M.E. now, whilst securing change for the future.



Our finances

After the receipt of an exceptional legacy in the previous year, our recorded total income for the year reverted to a more normal level of **£1.1m**.

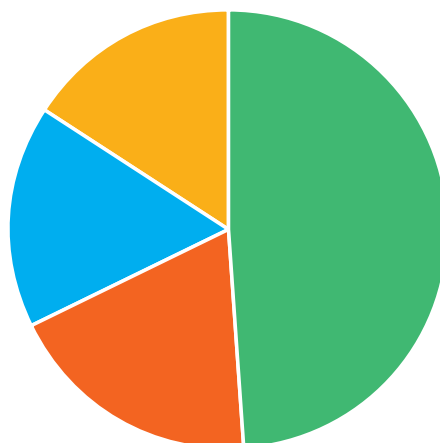
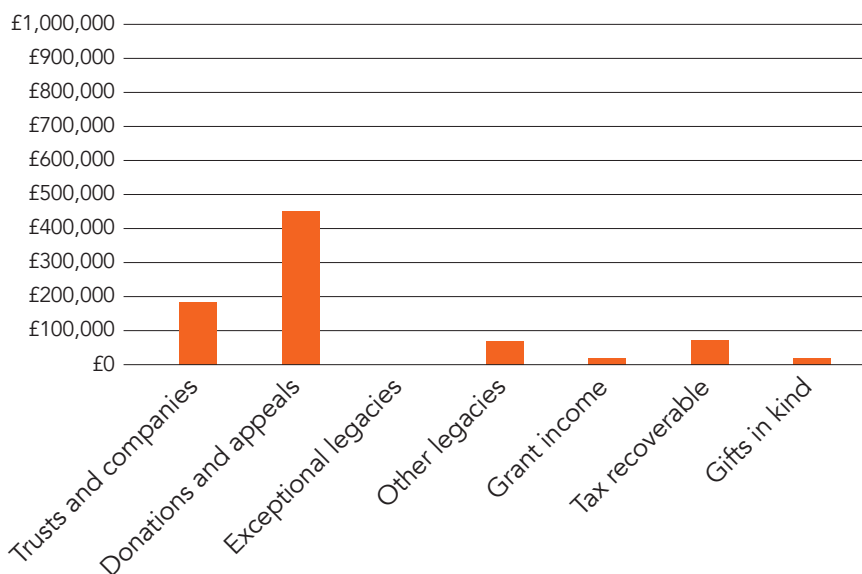
The Trustees and management agreed on an investment strategy in both staff and charitable activities for the current financial year and hence overall expenditure was £1.8million, an increase of 35% from the previous year.

The **net result** is a deficit of £0.7m. Despite this deficit, our current reserve position is still ahead of the Trustee target at £1.4m while our cash is also showing a healthy position at £1.3m. This will enable us to continue our investment into our current organisation and activities and set a platform for the longer-term growth and impact of the charity.

Income expended on charitable activities this year includes our one-to-one information, support and advocacy services, peer support for adults and young people, healthcare services, our campaigning and influencing work, and our investment in collaborative biomedical research.

To carry out all our activities effectively, we need committed and dedicated staff who bring the right skills, knowledge and experience to every area of our work. That's why over half (60%) of our total gross expenditure is on staff salaries.

In our strategy, we promise to raise £3 to £5 for every pound spend on fundraising, growing our income streams to delivery more services and support, and greater change.



This year, we spent:

£880k on our information, advocacy and peer support services for adults, young people and families with M.E.

£337k on our campaigning and influencing work.

£296k on our investment in collaborative biomedical research.

£281k on fundraising.



During 2022 – 2023 **we raised £3.23 for every £1 invested** in fundraising.

Summary Statement of financial activities

	2023 (£'000)	2022 (£'000)
Incoming Resources	1,123	2,497
Resources Expended	1,795	1,326
Net gains/(losses) on Investments	(3)	(2)
Net Movement in Funds	(675)	1,169
Fund balance 1 April 2023	1,380	–

Summary Balance Sheet

	2023 (£'000)	2022 (£'000)
Fixed Assets	64	75
Net Current Assets	1,317	1,979
Total Assets less Current Liabilities	1,380	2,055
General Funds	539	736
Designated Funds	668	1,067
Unrestricted Funds	1,207	1,803
Restricted Funds	174	252
Accumulated Funds	1,380	2,055

Our people, structure and governance

Public benefit

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. The annual report contains a fuller description of the public benefit that the charity provides on pages 2 – 15.

Trustees

The Trustees, for the purposes of Charity law and under the Company's Articles, are known as members of the Board of Trustees. Under the requirements of the Memorandum and Articles of Association, the members of the Board of Trustees are elected to serve for a period of three years, after which they must be re-elected at the next Annual General Meeting. Trustees can be elected for two three-year terms with the potential for an additional, exceptional, term. As the charity is also a Company Limited by Guarantee, the Trustees are also Directors of the Company.

The Board of Trustees of Action for M.E. meets quarterly with the Chief Executive and relevant staff to exercise corporate governance, give strategic direction, and manage the performance and achievement of corporate objectives. The Board also exercises fiscal oversight and takes the lead on strategic risk management. All Trustees receive comprehensive monthly financial management reports with a commentary by the Finance and Accounts Manager.

Day-to-day operations are overseen by the Chief Operations Officer (previously the Director of Business Support & Development), whose quarterly reports to the Board include a report against key performance indicators identified in our high-level delivery plan.

Our committees

Five sub-committees, established as part of the Board, operate according to clearly defined terms of reference. These committees hold delegated authority, acting as a resource to the Chief Executive and staff team, and make recommendations to the Board. They are made up of Trustees, staff and volunteers from outside the organisation including our Supporting Membership.

- The Audit, Finance and Fundraising Sub-Committee meets quarterly and reviews finances, risk controls, audit requirements, fundraising, and income generation activity to support and grow our work.
- The Public Affairs and Communications Sub-Committee meets quarterly and provides a steer for the charity's policy and influencing work at local, national and international levels.
- The Research Sub-Committee meets at least twice a year and monitors the charity's research-funded activity.
- The Remuneration and Nominations Sub-Committee meets as and when required, to make recommendations to the Board on senior appointments and related significant employment contract issues.
- The Healthcare Services Sub-Committee meets quarterly and provides oversight, scrutiny and assurances in all aspects of healthcare services.

All staff members, including the Chief Executive, have performance objectives that link directly to the charity's strategic objectives. Progress against these is monitored through regular one-to-one meetings and an annual performance review. An annual outcomes summary is provided to the Board to assist with

performance management responsibilities. All Trustees give their time voluntarily and receive no benefits from the charity. Any expenses reclaimed from the charity are set out in the notes to the accounts.

The Trustees aim to ensure that we have all the necessary skill-sets on the Board, and regularly review its constituency. Trustees are recruited by advertising openly, or through targeted recruitment if there is a skill that would be beneficial to the Board and that the charity is missing. We aim to have a minimum of 51% of Trustees on our Board who have direct experience of M.E.

Supporting Members vote on new appointments and the re-election of existing Trustees, with results subsequently confirmed at our Annual General Meeting) held this year in September 2022. Each new Trustee receives a full induction and has the opportunity to be paired with a 'buddy' for the first year on the Board, plus access to ongoing training.

Chief Executive

The Chief Executive is responsible for setting the strategic direction for the charity with the Trustees, leading its implementation, and holds delegated financial authority within parameters set out by our financial controls.

Collaborative partners

By working collaboratively with others who share our values, we can be more effective in achieving our aims and improving the lives of children, young people and adults with M.E. This includes other M.E. charities and patient organisations, health, social care and government and senior officials, and other decision-makers. As a member of a number of organisation and alliances, including Forward M.E., Disability Rights UK, Health Conditions in Schools Alliance, and the Disability Benefits

Our people, structure and governance

Consortium, we continue to build capacity, reach more people, and achieve more by working in partnership to achieve common goals.

We also provide secretariat support to the UK CFS/M.E. Research Collaborative, which led to the establishment of the M.E./CFS Biomedical Partnership, the group leading DecodeME.

Governing document

The organisation is a charitable company limited by guarantee and is a registered charity in England and Wales, and in Scotland, with further details provided on p 39. The Company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the Company being wound up, members are required to contribute an amount not exceeding £1.

Fundraising policy

Action for M.E. is regulated by the Fundraising Standards Board. Our approach to fundraising is set out in our fundraising policy which is reviewed annually by Trustees. The charity primarily fundraises from philanthropic sources (e.g. grant-giving bodies and individual donors) and fundraising events.

The charity recognises the need to conduct its fundraising within the context of recognised standards set out in the Institute of Fundraising's Code of Fundraising Practice, the Data Protection Act 1998/UKGDPR2021 and the CAP Code (Committee of Advertising Practice). We do not employ external professional fundraisers or companies.

Our fundraising policy stresses the critical importance that no individual should use their position in Action for

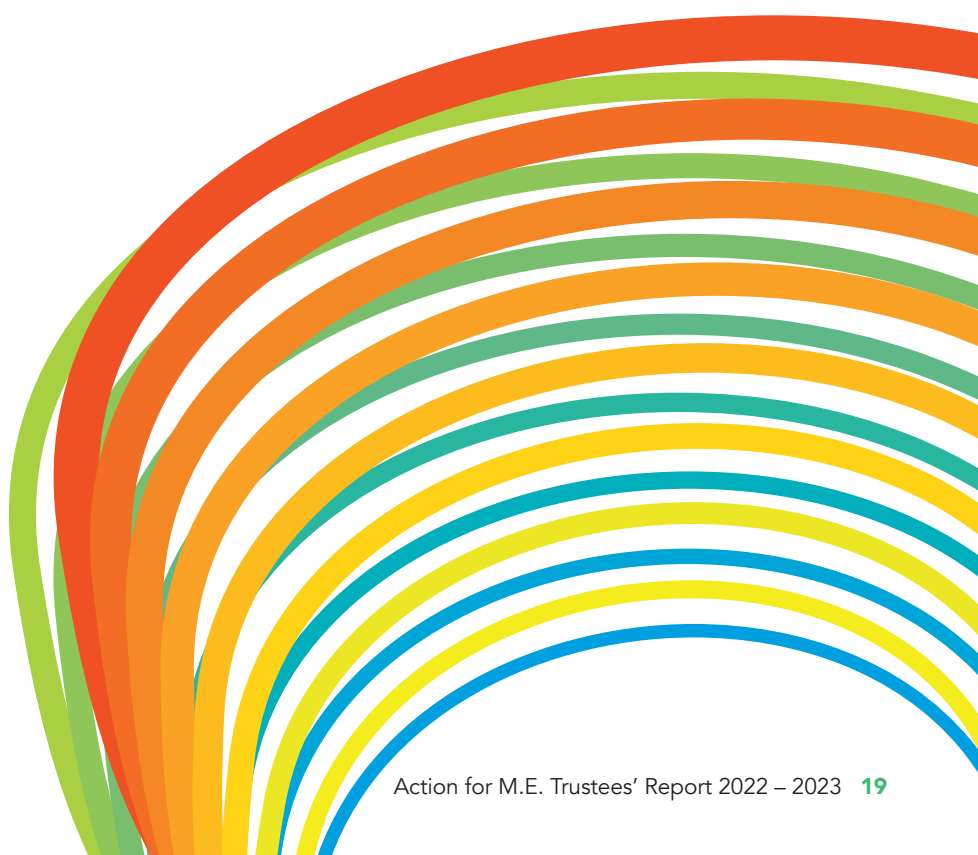
M.E. for personal gain, or to benefit others at the expense of the charity, our mission, or our reputation. It sets out that individuals must not act in any way that could be reasonably seen by others as compromising the independence and integrity of the charity; and that all activities must be carried out with honesty and integrity, with employees never knowingly misleading supporters. Any confidential information obtained must not be violated. The policy also sets out the way in which we deal with fundraising complaints.

Risk

The Chief Operating Officer and the Chief Executive have been responsible for the Risk Register, which is reviewed regularly by the Audit, Finance and Fundraising Committee and annually by the Board. Risks are categorised in a way that enables us to see the cumulative impact of risks and ensure that we take action protect the quality of work, reputation and income.

The largest risks facing our charity are a significant drop in income affecting our ability to provide services to people with M.E., and the charity adopts mitigation strategies to minimise the risk of this occurring. For example, by closely monitoring our income, with monthly reviews and reports to Trustees, with actions identified to minimise expenditure and increase income, we mitigate the risk that our income falls below projections. Safeguarding training covering both vulnerable adults and young people is included within the organisational induction policy, with refresher training delivered annually.

No serious incident reports were made to the Charity Commission regarding activity taking place 2022 – 2023.



Financial review

Statement of financial activities

As the leading M.E. charity in the UK, our distinguishing characteristic lies not just in supporting children, young people, and adults with M.E., but also in our comprehensive approach to care. This year, as we navigated through an evolving health landscape, our dedication to offering a unique blend of holistic support for people with M.E. remains undeterred. From providing essential information and support to those in need, to interagency signposting and pioneering advocacy services that aim to deliver meaningful practical help.

The development of our Healthcare Services department following our merger with The M.E. Trust last year sets us apart in the M.E. community. We are proud to offer access to an integrated team of professionals – from counsellors and physiotherapists to doctors and chaplaincy. This multi-disciplinary approach ensures that the mental, physical, and spiritual needs of our beneficiaries are met with expertise and empathy.

Our vision goes beyond immediate relief. This year we've invested deeply in the future, forging partnerships with groundbreaking initiatives like the DecodeME study and the World M.E. Alliance, alongside our tireless policy work pushing for positive action at the heart of Government and supporting PhD student working in the field of M.E. research.

Our annual Big Give Christmas Challenge fundraising campaign was successful for the sixth year running, raising £155k in income to support our services, medical education, and collaborative research work.

An investment strategy for both staff and charitable activities was agreed with Trustees and management which allowed Action for M.E. to both better serve those in immediate need, whilst helping to gain positive momentum in research and public

policy influence, and resulted in overall expenditure of £1.8 million.

At year-end, general reserves were £538K (down £197k against last year). In addition, the charity has designated reserves of £668k.

Restricted reserves were £174k (down £78k against last year) which will continue to be expended over the course of the next year on service delivery and biomedical PhDs. We continue to monitor our level of reserves to ensure we can maximise the work we do while ensuring the charity has a strong medium-term financial position.

Balance sheet

The deficit realised this year has decreased our accumulated funds and cash reserves at the year-end.

Funding sources

The primary financial contributions to Action for M.E. predominantly stem from charitable trusts, bequests, grassroots fundraising, event revenue, our Supporting Membership scheme, and donations from individuals. Additionally, Gift Aid and the sale of Christmas cards supplement our funding streams.

Our strength lies in our varied fundraising channels, ensuring we aren't excessively dependent on a singular revenue source. With an eye on fortifying this diversity, we will continue to allocate additional resources to our fundraising team, aiming to solidify our long-term revenue prospects.

This year, we are enormously grateful to the Jonathan Swire (1989) Trust, the De Laszlo Foundation, BBC Children in Need, the Sir James Reckitt Charity, and the Scottish Government (Neurological Support Framework Funding), for funding our support, medical education and research work.

Investment policy

Action for M.E. has an ethical investment policy and when finances allow, aims to invest in line with the values of Action for M.E. The charity invested £50k in the M&G Charibond which, as of March 2023, had a net value of £44k.

Reserves policy

The current policy is to maintain sufficient funds deemed 'free' (unrestricted) at no less than four times, and no more than twelve times, the monthly unrestricted operating costs of the charity. Previously, our policy was to hold 4 to 6 months of unrestricted reserves but was increased in November 2022 in light of the exceptional legacy received in the previous financial year. The charity ended the financial year with 9.7 months of unrestricted reserves (£1.2m) This is based on an average monthly unrestricted expenditure rate of £125k.

Grant-making policy

This policy sets the criteria and rules for making grants. This is reviewed annually, and grants are restricted to the funding of medical research.

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' annual report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). Company and charity law requires the Trustees to prepare financial statement for each financial year.

Under company law, the Trustees must not approve the financial statements unless they are satisfied that they give a true and fair view of the state of affairs of the charity and of the incoming resources and application of resources, including its income and expenditure, of the charity for the year.

Financial review

In preparing those financial statements the Trustees are required to:

- select suitable accounting policies and then apply them consistently
- observe the methods and principles in the Charities SORP
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements
- make judgements and accounting estimates that are reasonable and prudent
- prepare the financial statements on a going concern basis unless it is inappropriate to presume that the charity will continue in business.

The Trustees are responsible for keeping adequate and proper accounting records that are sufficient to show and explain the charity's transactions. They must disclose, with reasonable accuracy, at any times, the financial position of the charity and enable them to ensure that financial statements comply with the Charities and Trustee Investment (Scotland) Act 2005, regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended) and with the requirements of the Companies Act 2006.

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website, the Online M.E. Centre.

Legislation in the United Kingdom governing the preparation and dissemination of the financial

statements and other information included in annual reports may differ from legislation in other jurisdictions.

Auditor

Moore were re-appointed as our auditor at the 2022 Annual General Meeting.

Provision of information to Auditor

So far as each of the Trustees is aware at the time the report is approved, there is no relevant information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditor is aware of that information.

Small company provisions

This report has been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006.

Forward look

As we reflect on the past year, our commitment to improving the lives of those with M.E. has never been stronger. Moving into 2023-2024, we've laid out our priorities to amplify the impact we can create together.

A cornerstone of our upcoming initiatives is collaboration. Recognising the importance of a unified approach, we are focused on working hand-in-hand with a wide range of stakeholders to ensure the government's delivery plan for M.E. is effective and results in meaningful, positive change. By harnessing collective efforts, we aim to bridge gaps, spread awareness, and advocate for the rights of those affected by M.E.

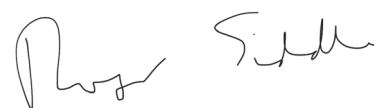
Our dedication to research remains paramount. This coming year, we are not only maintaining our momentum but also enhancing our efforts to ensure we deliver on our research goals. Our ultimate vision is to

uncover findings that lead to breakthrough treatments, significantly elevating the quality of life for individuals with M.E.

In line with our strategic plan, we are steadfast in our mission to expand information, support, and advocacy. By broadening our reach, we aim to ensure that every individual affected by M.E. has access to accurate information and unwavering support. Our focus on building an professional, accessible and above all useful holistic healthcare service stands testament to our dedication towards delivering well-being for our community.

To fund these ambitious initiatives, effective fundraising is essential. As we step into the new year, we have robust plans in place to drive fundraising campaigns that resonate with our cause and vision. We understand the magnitude of our goals, and with your continued support, we are confident in sourcing the required resources.

In conclusion, the year ahead is pivotal, there is still much to do. With your continued backing and our shared determination, together, I am confident that we will continue to make a real difference.



Roger Siddle
Chair of Board of Trustees and Directors



Jonathan Manuel
Director and Treasurer

Approved by the Board of Trustees and signed on its behalf on 29 September 2023.

Independent Auditor's report to the Members and Trustees of Action for M.E.

Opinion

We have audited the financial statements of Action for M.E. (the 'charitable company') for the year ended 31 March 2023 which comprise statement of financial activities, the balance sheet, the cash flow statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2023 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial

statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise

appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Report have been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report. We have nothing to report in respect of the following matters where the Companies Act 2006, the Charities Act 2011 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate and sufficient accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting

Independent Auditor's report to the Members and Trustees of Action for M.E.

- records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to prepare the financial statements in accordance with the small companies regime and take advantage of the small companies exemption in preparing the trustees' report.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' responsibilities set out on page 20-21, the trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when

it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Explanation as to what extent the audit was considered capable of detecting irregularities, including fraud

The objectives of our audit in respect of fraud, are; to identify and assess the risks of material misstatement of the financial statements due to fraud; to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatement due to fraud, through designing and implementing appropriate responses to those assessed risks; and to respond appropriately to instances of fraud or suspected fraud identified during the audit. However, the primary responsibility for the prevention and detection of fraud rests with both management and those charged with governance of the charitable company.

Our approach was as follows:

- We obtained an understanding of the legal and regulatory requirements applicable to the charitable company and considered that the most significant are the Companies Act 2006, UK financial reporting standards as issued by the Financial Reporting Council, and the Charities Act 2011.
- We obtained an understanding of

how the charitable company complies with these requirements by discussions with management and those charged with governance.

- We assessed the risk of material misstatement of the financial statements, including the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.
- We inquired of management and those charged with governance as to any known instances of non-compliance or suspected non-compliance with laws and regulations.
- Based on this understanding, we designed specific appropriate audit procedures to identify instances of non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of

Independent Auditor's report to the Members and Trustees of Action for M.E.

expressing an opinion on the effectiveness of the charitable company's internal control.

- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.

Evaluate the overall presentation, structure and content of the financial statements, including the disclosures,

and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Councils website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Chapter 3 of Part 8 of the Charities Act 2011 and regulations made under section 154 of that Act, and in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act

2005 and regulations made under section 44 of that Act. Our audit work has been undertaken so that we might state to the charitable company's members and the charity's trustees those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company, the charitable company's members as a body, and its trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Mark Powell, Senior Statutory Auditor
For and on behalf of Moore, Statutory Auditor

Moore is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006

Bath, UK
20 October 2023

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2023

	Notes	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2023 (£'000)	Total 2022 (£'000)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	685.7	127.4	813.1	2,288.4
Other trading activities	3	85.2	76.6	161.8	126.3
Investment income	4	8.5	–	8.5	1.1
Incoming resources from charitable activities	3	80.1	59.8	139.9	81.9
Total incoming resources		859.5	263.8	1,123.3	2,497.7
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	279.5	–	279.5	240.5
Fundraising trading: costs of goods sold and other costs		1.7	–	1.7	2.7
Charitable activities	5	1,171.6	341.6	1,513.2	1,082.9
Total resources expended		1,452.8	341.6	1,794.4	1,326.1
Net gains/(losses) on Investments		(3.4)	–	(3.4)	(2.2)
Net movement in funds	12	(596.7)	(77.8)	(674.5)	1,169.4
Reconciliation of funds					
Fund balances at 1 April 2022		1,803.2	251.6	2,054.8	885.5
Fund balances at 1 April 2023		1,206.5	173.8	1,380.3	2,054.8

All incoming resources and resources expended derive from continuing operations. The notes on p 28 to 38 form an integral part of these accounts.

Balance sheet

As at 31 March 2023 (company registered number 2906840)

	Notes	2023 (£'000)	2022 (£'000)
Fixed assets			
Tangible assets	9	19.4	27.4
Investments	10	44.3	47.8
Total fixed assets		63.7	75.2
Net current assets			
Debtors	11	148.3	1,056.4
Cash at bank and in hand		1,277.1	1,042.5
Total current assets		1,425.4	2,098.9
Creditors: Amounts falling due within one year	12	(108.8)	(119.3)
Net current assets		1,316.6	1,979.6
Total assets less current liabilities		1,380.3	2,054.8
Capital and reserves			
General funds		538.7	736.2
Designated funds	13	667.8	1,067.0
Unrestricted funds		1,206.5	1,803.2
Restricted funds	14	173.8	251.6
Accumulated funds		1,380.3	2,054.8

The accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 and in accordance with Financial Reporting Standard 102 and the Charities SORP (FRS 102). The notes on p 28 to 37 form an integral part of these accounts.



Roger Siddle
Chair of Board of Trustees and Directors



Jonathan Manuel
Treasurer

Approved by the Board of Trustees 29 September 2023

Action for M.E. cash flow statement for the year ended 31 March 2023

		2023 (£'000)	2022 (£'000)
Net cash flow from operating activities	See note a below	233.1	365.1
Net cash flow from investing activities	See note b below	1.5	(11.8)
Net increase in cash and cash equivalents		234.6	353.3
Cash and cash equivalents at beginning of period		1,042.5	689.2
Cash and cash equivalents at end of period		1,277.1	1,042.5

Notes to the cash flow statement

a Cash flows from operating activities

	(£'000)	(£'000)
Net movement in funds	(674.5)	1,169.3
Depreciation	15.1	13,118
(Gains)/losses on investments	3.4	2,249
Financial income	(8.6)	(1,058)
	(664.6)	1,183,620
(Increase)/decrease in debtors	908.1	(863,608)
(Decrease)/increase in creditors	(10.4)	45,048
NET CASH FROM OPERATING ACTIVITIES	233.1	365,060

b Cash flows from investing activities

	(£'000)	(£'000)
Purchase of tangible fixed assets	(7.1)	(12,862)
Interest received	8.6	1058
Investment in financial assets	–	–
NET CASH FROM INVESTING ACTIVITIES	1.5	(11,804)

Analysis of changes in Net Funds

	At 01.04.2022 (£'000)	Cash Flow (£'000)	At 31.03.23 (£'000)
Cash at Bank	1,042.5	234.6	1,277.1

Notes to the accounts

1 Accounting policies

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) as updated by Bulletin 1 – ('Charities SORP (FRS 102)'), the Financial Reporting Standard applicable in the UK and Republic of Ireland ('FRS 102') and the Companies Act 2006.

Action for M.E. is a private company limited by guarantee and registered in England and Wales. Its registration details are given on p 39. It meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s). The financial statements are prepared on a going concern basis. The Trustees consider that there are material uncertainties over going concern. The preparation of financial statements in compliance with FRS 102 Section 1A Small Entities requires the use of certain critical accounting estimates. It also requires management to exercise judgement in applying the accounting policies.

Recognition of liabilities

Liabilities are recognised on the accruals basis.

Investments

Investments are valued at mid-market value at the year-end. Realised and unrealised gains or losses are credited or charged to the relevant fund in the Statement of Financial Activities.

Incoming resources

Incoming resources, including bank interest receivable, are accounted for on a receivable basis when the Charity is legally entitled to the income and the amount can be quantified to the income and the amount can be quantified with reasonable accuracy.

Donated services and facilities are included as voluntary income at their estimated value to the Charity when received, and under the appropriate expenditure heading depending on the nature of the service of facility provided. Time donated by volunteers is not recognised in the financial statements as this cannot be reliably valued. For Legacies, entitlement to funds, the measurable amount of the legacy and the probability that it will be received inform the decisions around recognition and receipt of legacy funds. Deferred income, where appropriate, is accounted for as above.

Resources expended

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to that category. Where costs cannot be directly attributed to particular headings, they have been allocated to activities on a basis consistent with the use of resources.

Support costs are allocated to operational and fundraising functions on the basis of their use of central support services.

Grants payable are payments made to third parties in furtherance of the Charity's objectives. Single or multi-year grants are accounted for when either the recipient has a reasonable expectation that they will receive a grant and the Trustees have agreed to pay the grant without condition, or when the recipient has a reasonable expectation that they will receive a grant and any condition attaching to the grant is outside the control of the Charity. Where a grant includes specific performance terms, grants payable are recognised as performance milestones are met.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing or the amount of the grant.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities.

Charitable expenditure comprises those costs incurred by the Charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs include all expenditure not directly related to charitable activity. The Trustees have applied what they consider to be reasonable judgements in apportioning such costs between direct charitable costs and support costs. The central office functions such as general management, payroll administration, budgeting and accounting, information technology, human resources and financing, are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of the cost allocation is explained in note 5 to the accounts.

Governance costs are the costs associated with the governance arrangements of the Charity which relate to the general running of the Charity as opposed to those costs

associated with fundraising or charitable activity. Included within this category are the cost of audit fees and costs linked to the strategic management of Charity.

Governance costs are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of allocation is explained in note 5 to the accounts.

Fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Items of less than £500 are not capitalised. Depreciation has been provided at the following rates in order to write off the cost of the assets (less their expected residual value) over their estimated useful economic lives. Officer Equipment – 25% on the straight line method.

Pensions

The Charity operated an occupational pension scheme. Contributions are charged to the Statement of Financial Activities as they become payable in accordance with the rules of the scheme. The scheme is a defined contribution scheme.

Taxation

As a registered Charity whose income and gains are used solely for its charitable purposes, the Charity falls within the exemption for corporation tax and as such has had no tax charge for this accounting period. The Charity operates a partial-exemption method for the recovery of certain VAT. The amount of VAT that cannot be recovered is included in support costs and is £65,334 (£25,615 in 2021).

Operating lease agreements

Rentals applicable to operating leases when substantially all of the benefits and risks of ownership remain with the lessor are charged against profits on a straight line basis over the period of the lease.

Financial instruments

The Charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. Basic financial instruments are initially recognised at transaction value and subsequently measured at their settlement value. The Charity does not acquire put options, derivatives or other complex financial instruments.

2 Judgements in applying accounting policies and key sources of estimation uncertainty

In preparing these financial statements the Trustees have had to make the following judgements:

- Apportionment of staff time on specific activities has been made in the absence of formal timesheets and therefore based on the role profiles and work-plans of the individuals, as in previous years.
- The valuation and recognition of pending legacies throughout the year and specifically at the year-end is based on the charity's entitlement to funds, the availability of sufficiently reliable estimates of the amount indicated for the legacy and the probability that it will be received.

3 Details of incoming resources

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2023 (£'000)	Total 2022 (£'000)
Trusts and companies	129.7	58.8	188.5	307.2
Donations and appeals	404.5	39.1	443.6	364.5
Exceptional legacies	–	–	–	1,277.1
Other legacies	66.5	–	66.5	31.0
Grant income	–	21.5	21.5	100.6
Tax recoverable	63.3	8.0	71.3	62.0
Gifts in kind	21.7	–	21.7	146.0
	685.7	127.4	813.1	2,288.4
Other trading activities				
Lotteries and raffles	9.2	–	9.2	10.4
Christmas cards	3.8	–	3.8	5.3
Supplement commission	2.3	–	2.3	2.4
Merchandise	0.4	1.5	1.9	0.3
Other	69.5	75.1	144.6	107.9
	85.2	76.6	161.8	126.3
Incoming resources from charitable activities				
Subscriptions	80.1	–	80.1	74.9
Healthcare services	–	58.8	58.8	7.0
	80.1	58.8	139.9	81.9

Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy for work related to Ph.D. contracts has been valued at £21,747 based on number of hours worked.

Details of 2022 income	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2022 (£'000)
Donations and legacies			
Trusts and companies	161.2	146.0	307.2
Donations and appeals	318.9	45.6	364.5
Exceptional legacies	1,277.1	–	1,277.1
Other legacies	31.0	–	31.0
Grant Income	9.4	91.2	100.6
Tax recoverable	55.9	6.1	62.0
Gifts in kind	128.1	17.8	146.0
	1,981.6	306.7	2,288.4
Other trading activities			
Lotteries and raffles	10.4	–	10.4
Christmas cards	5.3	–	5.3
Supplement commission	2.4	–	2.4
Merchandise	0.2	0.1	0.3
Other	45.9	62.0	107.9
	64.2	62.1	126.3
Incoming resources from charitable activities			
Supporting Membership	74.9	–	74.9
Healthcare services	–	7.0	7.0
	74.9	7.9	81.9

4 Investment income

	2023 (£'000)	2022 (£'000)
Interest from cash investments in the UK	8.5	1.1
	8.5	1.1

5 Resources expended

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2023 (£'000)	Total 2022 (£'000)
Costs of generating voluntary income				
Staff costs	43.6	–	43.6	46.8
Direct fundraising costs	19.9	–	19.9	13.9
Support costs – see below	216.0	–	216.0	179.8
	279.5	–	279.5	240.5
	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2023 (£'000)	Total 2022 (£'000)
Charitable activities				
Information and support services	693.3	186.4	879.7	657.4
Campaigning and influencing work	333.4	3.9	337.3	176.6
Collaborative biomedical research	145.0	151.3	296.3	248.9
	1,171.7	341.6	1,513.3	1,082.9

Costs of charitable activities for unrestricted funds are analysed as follows:

	Activities undertaken directly	Support costs as below	Total (£'000)
Activity			
Information and support services	304.4	388.9	693.3
Campaigning and influencing work	203.8	129.6	333.4
Collaborative biomedical research	32.7	112.3	145.0
	540.9	630.8	1,171.7

Central support and governance costs are allocated as follows according to full-time equivalent number of staff per activity.

	Governance costs as below	Admin costs finance	Property management	Office management	IT admin costs	Total (£'000)
Support costs						
Information and support services	19.2	55.3	19.4	270.8	24.2	388.9
Campaigning and influencing work	6.4	18.4	6.4	90.3	8.1	129.6
Research	5.5	16	5.6	78.2	7.0	112.3
	31.1	89.7	31.4	439.3	39.3	630.8
Fundraising	10.6	30.7	10.8	150.4	13.5	216.0
	41.7	120.4	42.2	589.7	52.8	846.8

Office costs include £21,747 (£145,955 in 2022) for professional services in kind.

	2023 (£'000)	2022 (£'000)
Governance costs		
Administrative salaries – based on time spent	30.7	25.5
Indemnity insurance for Trustees	2.1	2.3
Trustees' expenses	1.0	0.5
Auditors' fees	6.9	6.9
Design and printing	1.0	1.0
	41.7	36.2

	2023 (£'000)	2022 (£'000)
Grant activities		
The University of Edinburgh – PhD. in biomedical research	9.0	–
The University of Oxford- PhD. In biomedical research	15.0	–
Kings College London – PhD. in biomedical research	14.7	–
	38.7	–

Details of 2022 expenditure	Unrestricted funds (£'000)	Restricted funds (£'000)	2022 (£'000)
Costs of generating voluntary income			
Staff costs	46.8	–	46.8
Direct fundraising costs	13.9	–	13.9
Support costs – see below	179.8	–	179.8
	240.5	–	240.5
Charitable activities			
Information and support services	420.3	237.1	657.4
Campaigning and influencing work	176.6	–	176.6
Collaborative biomedical research	84.2	164.7	248.9
	681.1	401.8	1,082.9

Costs of charitable activities for unrestricted funds are analysed as follows:

	Activities undertaken directly	Support costs as below	Total (£'000)
Activity			
Information and support services	86.9	333.4	420.3
Campaigning and influencing work	86.7	89.9	176.6
Collaborative biomedical research	–	84.2	84.2
	173.6	507.5	681.1

Central support and governance costs are allocated as follows according to full-time equivalent number of staff per activity.

	Governance costs as below	Admin costs finance	Property management	Office management	IT admin costs	Total (£'000)
Support costs						
Information and services	17.6	31.6	19.4	242.7	22.1	333.4
Campaigning and influencing work	4.7	8.5	5.2	65.4	6.0	89.8
Research	4.5	7.9	4.9	61.4	5.6	84.3
	26.8	48.0	29.5	369.5	33.7	507.5
Fundraising	9.5	17.0	10.4	130.9	12.0	179.8
	36.3	65.0	39.9	500.4	45.7	687.3

6 Net movement in funds

	2023 (£'000)	2022 (£'000)
This is stated after charging:		
Operating lease	36.6	31.8
Depreciation of owned fixed assets	15.1	13.1
Auditor remuneration	6.9	6.9
Trustees' expenses	1.0	0.4
Pension costs	67.5	49.2

Funds belonging to the Charity have been used for the purchase of insurance to protect its Trustees in their capacity as Trustees. The sum expended by the Charity on such insurance for the year to 31 March 2022 was £2,068 (£2,287 in 2022).

7 Staff costs and emoluments

	2023 (£'000)	2022 (£'000)
Gross salaries	959.5	733.2
Employer's National Insurance	84.8	56.0
Pension contributions	31.9	22.8
	1,076.2	812.0

Numbers of full-time employees or full-time equivalents

	2023	2022
Engaged on charitable activities	25	27
Engaged in fundraising activities	6	5
Engaged on management and administration	9	5
	40	37

The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:

	Number	Number
£60,000 - £70,000	1	–
£80,000 - £90,000	–	1
£100,000 - £110,000	1	–
Total	2	1

The Charity considers its key personnel to comprise the Trustees and the Chief Executive Officer. The total employment benefits including employer pension contributions of the key personnel were £102,249 (£89,733 in 2022).

The Charity remains grateful for the work of its volunteers. The role and scope of work undertaken varies, and takes into account the fluctuating energy levels of the volunteers, many of whom are affected by M.E.

The time donated by volunteers is not recognised in the financial statements as this cannot be reliably or consistently valued.

8 Trustees

The Trustees all give freely their time and expertise without any form of remuneration or other benefit in cash or kind.

Total expenses reimbursed to Trustees or met by the Charity. These expenses were made up of two Trustees for travel and accommodation for the purpose of attending Board meetings.

Amounts of expenses incurred by Trustees that were donated back to the Charity.

There were no related party transactions up to 31 March 2023.

2023 (£'000)	2022 (£'000)
–	–
1	0.5
–	0.3

9 Tangible fixed assets

Office equipment (£'000)

Cost	
At 1 April 2022	79.8
Additions for year	7.0
Disposals in year	–
At 31 March 2023	86.8
Depreciation	
At 1 April 2022	52.3
Charge for year	15.1
Disposals in year	–
At 31 March 2023	67.4
Net book value	
At 31 March 2022	27.4
At 31 March 2023	19.4

10 Investments

Market value	
At 1 April 2022	47.7
Revaluations	(3.4)
At 31 March 2023	44.3
Net book value	
At 31 March 2022	47.7
At 31 March 2023	44.3

There were no investment assets outside of the UK.

11 Debtors

	2023 (£'000)	2022 (£'000)
Trade debtors	67.6	66.7
Prepaid expenses	31.5	24.0
Due from HMRC	0.2	11.2
Accrued income	49.0	954.5
	148.3	1,056.4

12 Creditors: amounts falling due within one year

	2023 (£'000)	2022 (£'000)
Trade creditors	43.8	63.4
Accrued expenses	36.7	32.3
Unpaid pension contributions	5.5	5.3
Other taxation and social security costs	22.8	18.3
	108.8	119.3

13 Funds

	General funds (£'000)	Designated funds (£'000)	Total (£'000)	
Statement of unrestricted funds				
Balance at 1 April 2022	736.2	1,067.0	1,803.2	
Transfer between funds	359.0	(359.0)	–	
Surplus for year	(556.5)	(40.2)	(596.7)	
Balance at 31 March 2023	538.7	667.8	1,206.5	
	Tangible fixed assets (£'000)	Cash	Other Net current assets (£'000)	Total (£'000)
Analysis of net assets between funds – current year				
Unrestricted funds:				
General funds	63.7	459.3	15.7	538.7
Designated funds	–	667.8	–	667.8
	63.7	1,127.1	15.7	1,206.5
Restricted funds	–	150.0	23.8	173.8
	63.7	1,277.1	39.5	1,380.3

	Tangible fixed assets (£'000)	Cash	Other Net current liabilities (£'000)	Total (£'000)
Analysis of net assets between funds – prior year				
Unrestricted funds:				
General funds	75.2	630.5	30.5	736.2
Designated funds	–	242.0	825.0	1,067.0
	75.2	872.5	855.5	1,803.2
Restricted funds	–	170.0	81.6	251.6
	75.2	1,042.5	937.1	2,054.8

14 Restricted funds

	Opening balances (£'000)	Incoming resources (£'000)	Outgoing resources (£'000)	Closing Balances (£'000)
Movements in restricted funds				
Research	164.2	43.4	79.7	127.9
DecodeME	–	71.6	71.6	–
Information and Support Service	18.0	28.5	31.5	15.0
Learn about M.E.	10.7	21.5	21.2	11.0
M.E. Advocacy	37.9	–	30.0	7.9
Advocacy Services	1.8	22.6	21.1	3.3
Breaking Isolation	1.4	8.8	6.5	3.7
Healthcare Services	–	63.5	63.5	–
M.E. Friends Online	8.5	–	8.5	–
Listen to M.E.	4.1	–	4.1	–
World M.E. Alliance	–	3.9	3.9	–
Printed resources	4.9	–	–	4.9
	251.5	263.8	341.6	173.7

Research – donations received from donors wishing to see advances in research.

DecodeME – funding awarded jointly by the Medical Research Council and National Institute for Health Research for our role in co-leading this research project as part of the ME/CFS Biomedical Partnership.

Information and Support Service – funding to increase our reach to people of all ages affected by M.E., including family members, offering information, resources, signposting, support and understanding.

Learn about M.E. – funding from Scottish Government's Neurological Framework to promote a free online learning module for GPs, medical students and allied health professionals, working with the ME Association, #MEAction Scotland and the 25% ME Group and complemented by our Learn about M.E. podcast series.

Visit: www.actionforme.org.uk/learn-about-me

M.E. Advocacy – funding from the ALLIANCE Self-Management Fund to work with volunteers to deliver direct advocacy and self-advocacy workshops to enhance self-management of adults with M.E. in Scotland.

15 Pension commitments

The Charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable to the scheme and is disclosed in note 7. Contributions in the sum of £5,470 (£5,258 in 2022) were outstanding at the balance sheet date.

16 Operating leases

At the year end the Charity had commitments under non-cancellable operating leases as set out below.

	Total Leases 2023 (£'000)	Total Leases 2022 (£'000)
Operating lease payments falling due:		
within one year	35.9	30.9
within two to five years	143.8	122.4
over five years	–	30.3
	179.7	183.6

17 Contingent assets

During the year the Charity has been advised of a number of legacies. The value of some legacies that are dependent on the sale of an estate could not be estimated within the accounting period and will be recognised as income in the financial year they become certain.

18 Research funding commitments

The Charity is committed to funding a number of research grants over the forthcoming years subject to certain performance conditions being met. The Charity is committed to further expenditure of £181,829 of which £89,665 is to be spent in the year to 31 March 2024.

Legal and administrative details

Action for M.E.

Registered charity No 1036419
Registered in Scotland SC040452
Incorporated on 10 March 1994
Company registration number 2906840

Registered office
42 Temple Street
Keynsham
Bristol BS31 1EH

Bankers

The Royal Bank of Scotland
144 New Street
Birmingham B2 4NY

Auditor

Moore
30 Gay Street
Bath BA1 2PA

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Clare Francis MBE

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Sue Hardy
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David Leigh
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(joined September 2022)

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