Action for ME

Annual report and accounts

2024/25

Artist, Alison Larkman, ***'I would be here if I could'***
© Sasha Snow

Contents

Trustees' annual report

04 Investing for the future

05 CEO's message

06 Chair's message

07 Our impact in 2024/25

09 We're changing lives: Support Services

13 We're changing lives: Healthcare Services

17 We're changing futures: accelerating ME research

21 We're changing futures: campaigning for change

Thank you

23 Lee's story

24 Danny's story

25 Fundraising spotlight

26 A special thank you

27 Our finances

29 Our people, structure, and governance

31 Financial review

Accounts

33 Independent auditor's report

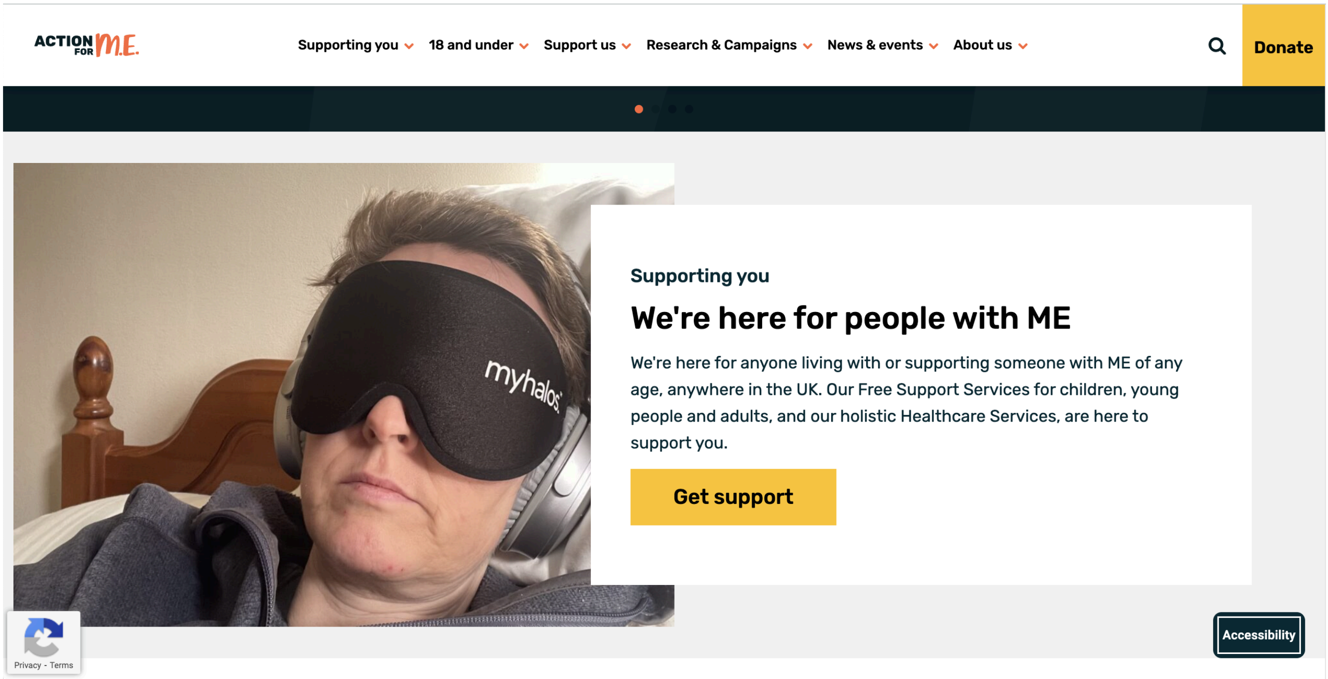
36 Statement of financial activities

37 Balance sheet

38 Cash flow statement

39 Notes to the accounts

Investing for the future



Supporting you

We're here for people with ME

We're here for anyone living with or supporting someone with ME of any age, anywhere in the UK. Our Free Support Services for children, young people and adults, and our holistic Healthcare Services, are here to support you.

Get support

Our new website

Since our 2023/24 Annual Report, we took the decision to invest in our future by developing a new, more accessible website and refreshing our brand.

The world, and our organisation, has changed dramatically since our previous website was created over a decade ago. It was therefore no longer fit for today's digital audiences, limiting our growth and opportunities to take action and raise even more vital awareness and funds to support even more people affected by ME.

Our previous website no longer met modern accessibility standards and people were reporting issues such as hard-to-find resources and information. Furthermore, our ME Friends Online forum also urgently needed updating to meet the needs of its users.

We knew this needed to change.

We want our information, Services, and wider work to be accessible to as many people as possible, ensuring that people affected by ME can receive the understanding and support they deserve, when they need it most.

Collaboration

We knew that for this work to have the greatest benefit for people affected by ME, their views and experiences had to remain constant throughout the process.

Over the course of a year, over 300 of our members, supporters, service users, and other key stakeholders helped shape this work. They fed directly into the process and decision-making.

We conducted various surveys and established a project Steering Group, comprising our staff, Trustees, and people with direct lived experience to ensure that people with ME were directly involved.

Our new website was user-tested by over 30 individuals, all with differing relationships to our organisation. We listened to, and acted on, their constructive feedback and are still committed to continuing to work collaboratively to further improve the site and our wider work.

CEO’s message

The proudest moment of my career happened as a result of our collaboration to deliver the initial DecodeME results.

2024/25 was the year we focused on the genetic analysis and it was an emotional moment when we announced our initial results on 6 August 2025. Our findings identified eight genetic signals, providing the first robust evidence that genes contribute to the chances of developing ME. These signals show where people with ME differ from those without and are linked to the immune and nervous systems.

These landmark findings reflect the lived experience of so many people with ME, providing validation and exciting new avenues for research.

Taking action now to provide vital support and healthcare to people with ME today, while driving change for the future continues to be at the heart of what we do.

With an estimated 1.35m people in the UK with ME or ME-like symptoms, including the hallmark post-exertional malaise, we continue to provide information, support, advocacy, and healthcare services. These services are called a “lifeline” by many.

From April 2024 to March 2025, our Information & Support (I&S) service made over 1,700 direct contacts with people affected by ME, providing them with vital support when they needed it most. This work has been impressively supported by our Family Support, Adults Advocacy, and Children and Young People’s services.

Our Services are impactful and feedback from our Support and Healthcare Services continues to be very positive.


92% had an increased understanding of their rights & options.


85% had an increased knowledge of support


90% felt less isolated.


77% felt more confident communicating with professionals.

- Information & Support service feedback

> **“I really appreciate Dr Kerr’s efforts to help treat symptoms/co-morbidities commonly associated with ME. He is knowledgeable and kind and easy to talk to. It’s extremely rare and validating to encounter a doctor who is aware of how serious ME can be and actually takes steps to help patients.”**
>
> - Doctor service user

Alongside the ongoing work on the LOCOME study and the ME Genetics Centre of Excellence, we also announced a new partnership with experts from Oxford Nanopore Technologies (ONT) and the University of Edinburgh. Sequence ME and Long Covid will build on DecodeME to undertake whole genome sequencing using ONT’s novel technology. We are pushing hard to secure the funds to start this critical scientific study.

Change has to be made. So, working with policy and decision makers to drive change is critical. During the year, we continued to build our army of Parliamentary Champions and, at the time of writing, this has grown to almost 20. Our Parliamentary Champions and the All-party Parliamentary Group (APPG) on ME, for which we provide the joint-Secretariat for, have pushed hard in calling for the publication of the Final Delivery Plan on ME/CFS.

During the year, questions were raised in Parliament, letters written, and meetings held, which eventually resulted in the Plan’s publication in July 2025. As a Task and Finish Group member, I look forward to continuing to work with the Department of Health and Social Care and other other colleagues to ensure the Plan is not only implemented, but exceeded.

I would like to thank you all for continuing to support us to improve the lives of people affected by ME now, whilst taking action to secure positive change for the future.

Sonya Chowdhury

Sonya Chowdhury
Chief Executive,
Action for ME

Chair's message

Because real change doesn't just happen, action and impact are at the heart of everything we do.

While working to secure change for the long-term future, we meet needs now through the provision of direct support. Our strategy has four main pillars:

Direct support - helping people today with information, support, and advocacy

Latest research indicates there are at least over 400,000 people with ME in the UK. With the inclusion of those with long Covid who have ME-like symptoms, including post-exertional malaise, we know this figure rises to around 1.35m. We have seen the levels of need and complexity for these people increase further over this last year, as demand for support continues to outstrip the capacity we have.

Direct support - providing Healthcare Services to those who need it

Our Healthcare Services provide doctor, physiotherapy, counselling, and multi-faith chaplaincy support and, regrettably, we know waiting times have been high for some. We recruited an additional doctor to assist with this, which has helped, and we continue to strive to match supply to meet that demand, providing over 2,500 consultations across the year.

Long-term change - accelerating breakthrough research

The DecodeME study has been a core focus. On 6 August 2025, we were delighted to see its results published, providing clear and robust evidence for the link between genetics and ME. We hope this will be the foundation for increased levels of research.

DecodeME has not been our only area of research activity. We have worked to catalyse new collaborations to increase research and research funding, with new partnerships being announced and an event at Windsor Castle, in partnership with St. George's House and funded by a donor, attracting international guests with whom we are now working.

During the year, we led the work on a funding application for an MRC Strategic Partnership grant. The PRIME project received a positive outcome just after the financial year and will start in October this year.

Long-term change - lobbying key decision makers, as a voice of the community

We have continued to grow our public affairs work, engaging with the new government and growing our network of parliamentarians championing the needs of people with ME in a range of different ways.

We were pleased to see the National Delivery Plan for ME/CFS was finally published in July this year, following many promises and many delays. The cup remains half full - while it is great progress to see people with ME finally recognised and steps being taken to address their needs for support, the Plan could go so much further - especially in the area of increased funding. We will continue in our endeavours to address this problem.

We have made great strides this last year, but it is nowhere near enough. With needs and demand increasing, action on a wider scale is needed and we continue to partner where we can, when we can.

We are always being asked to do more, and we want to do more but, as a small charity with relatively limited resources, we must remain focused on our strategic aims.

I must once again thank you - our donors, funders, fundraisers, supporters, and volunteers for your continued support, helping our income for the year reach £1.36m.

Despite this relative success, our income continues to remain a priority to deliver on our goals - and if we had more, we could do more or go faster.

Day in and day out, my colleagues make critical and valuable contributions to individuals and to the community. I would like to thank them, and my fellow Trustees, for their continued hard work, passion, and commitment to improving the lives of people with ME.

Roger Siddle

Roger Siddle
Chair,
Board of Trustees

Our impact in 2024/25

"This continues to be an outstanding service. Now that I've experienced this illness at severe level with a lot of cognitive dysfunction and at a moderate level with more normal cognitive functioning, I have even more evidence of the responsiveness to the many different kinds of practical needs, distress, confusion and disorientation that people experience going through this. I find it very hard to imagine how I would have coped with this year without this service and the highly skilled support provided."

- Information & Support service user

Over 1,700 enquiries from our free Information & Support service resulted in increased support for people with ME

Improving lives and investing in research through £276k raised in our 8th Big Give Christmas Challenge

102 children & young people attended our Breaking Isolation workshops, reducing loneliness

100% of our Family Support service users reported increased confidence in communicating with professionals

"Your team were incredibly helpful, I was able to get advice on what to do next and pointed in the direction of legislation I could use to advocate for myself, and after weeks and weeks of going round in circles with my local council I was able to resolve my problem almost instantly after getting help and advice from your team!"

- Adults Advocacy service user

100% of our Adults Advocacy service users felt better-resourced to self-advocate

864 healthcare professionals increased their understanding of ME through the Learn About ME online module

We provided **128** bursaries to improve accessibility of our Healthcare Services

100% of young people felt less isolated as a result of our free Young People's Counselling

95% of our Information & Support service users reported being satisfied or very satisfied with the service

Support and information accessed more than **1.3m** times through our website and online forums

We're changing lives

Our free Support Services provide information, support, and advocacy to people affected by ME, when they need it most.

Debi’s story

Following a bout of glandular fever when she was 17, Debi struggled through her A Levels and started training to be a nurse - a dream of hers. Sadly, a year into her course, an adverse reaction to a Hepatitis B vaccine caused her health to rapidly deteriorate.

“I collapsed on the ward one evening. I saw a doctor from occupational health and he diagnosed me with ME. I had heard of it but didn't know anything about it.”

Due to her ME, Debi had to give up her dream of becoming a nurse and move back in with her parents.

“I was virtually bedbound and my mum had to feed me. Then it got so that I couldn’t even chew because of the fatigue. One by one my friends dropped off. They continued on their journey and my life stood still. That was over 30 years ago now. Today I am lucky enough to have mild to moderate symptoms. I still feel very sad that I couldn’t finish my nursing training.”

One year ago, Debi’s 16-year-old daughter started showing symptoms.

“She was exhausted all the time. My heart sank.”

The exhaustion continued and Debi was becoming extremely worried about her daughter. She contacted the GP but was told she would need to wait 3 months for a paediatric appointment.

Our free Information & Support service was able to provide guidance to Debi on how to request support for her daughter at school, and what to expect in response.

“I felt desperate. I contacted Action for ME. I explained our situation and I had a very kind and thorough email back almost straight away. They understood my concern for my daughter, especially with her GCSEs coming up. They explained to me how to go about getting some support from her school.”

“They were there for me when I really needed support and advice. Immediately, I felt completely supported and understood. I felt like I had the support to help my daughter and that we weren’t alone. I felt like someone was on my side and had walked me through what my options were. I felt validated and heard and much less anxious. It has meant a lot.”

"Now I don't feel so alone"

Living with ME often means facing disbelief, isolation, and a lack of understanding. Our Services exist to change that. We empower people with ME to secure effective access to the information, support, and advocacy they need.

"Very compassionate, understanding, and lots of really helpful advice and resources I haven't been able to find anywhere else. I was lost, alone, and feeling very scared and vulnerable. Now I don't feel so alone and I know what next steps to take."
- Information and Support service client

This year, people with ME, and the professionals that support them, made more than 1,700 enquiries to our Information and Support, Advocacy, and Family Support services. Securing tailored information and accessible resources from us helped them navigate and access healthcare, social care, employment, and education.

"Having a team like Action for ME around to support you not only makes you feel less alone in all of it, but for me was also a really empowering experience that left me feeling much more optimistic about the future and much more "seen" as an adult worth someone's time and support, rather than as a number taking up space in someone's inbox."
- Advocacy Service client, who now volunteers as part of our Advocacy Steering Group to shape service development.

More than 100 children and young people with ME took part in our online Breaking Isolation (BI) workshops and fun forum drop-ins as part of our Young People's Community. Many attend more than once to make friends and talk about what matters to them.

"Meeting other children like me who understand what it is like and doing fun activities was the most helpful thing."
BI workshop participant, age 11

Adults with ME told us how much they value our regular Mindfulness workshops, launched in April 2024 and co-facilitated by experienced volunteer, Alice.

"The online Mindfulness session enabled me to relax and pay attention to my needs. I am housebound so these online sessions are so helpful to me. Alice did a brilliant session, she was a very calming voice, and we were able to ask questions at the end of the session which was useful."
- Workshop participant

Advancing patient care

Thanks to funding from the Scottish Government for our Learn About ME project, hundreds of GPs and other professionals had the opportunity to access Dr Nina Muirhead's highly-rated e-learning CPD module on ME/CFS, alongside our Learn About ME podcasts and webinars, on topics including paediatric ME and severe ME.

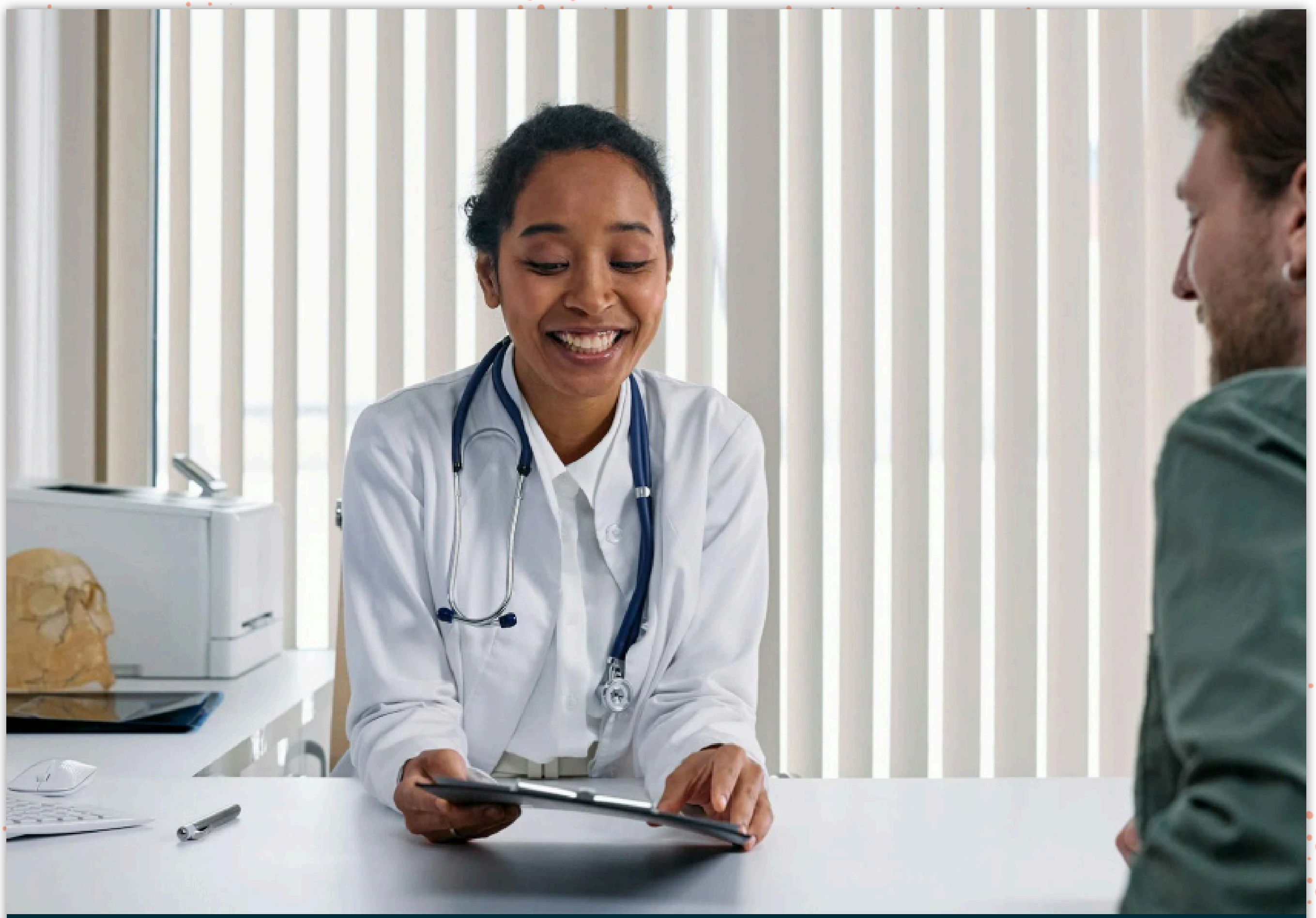
"Beyond teaching me about ME/CFS, the project really exemplifies the power that collaboration can have in advancing patient care and clinical practice, something I've found truly inspiring."
- Bhanu Wahi-Singh, first prize winner in our Learn About ME student essay competition

The essay competition saw nearly 30 entries from students across Scotland. In 2025, thanks to our Big Give Christmas Challenge Campaign, we are taking this competition nationwide.

At the end of the year, our Family Support Service delivered training to a school in Kent. As a result, 93% of attendees said they felt more confident supporting pupils with ME, while 87% said they felt more well-resourced to understand the condition.

We continue to deliver training to more professionals to help improve the lives of their patients, pupils, and clients with ME.

Bhanu Wahi-Singh
First-prize winner of our Learn About ME medical student essay competition



We're changing lives

Our holistic Healthcare Services provide tailored, person-centric care and support, where specialist care is often absent elsewhere.

ACTION FOR M.E.

COMMUNITY FUND

PRUDENCE TRUST

Dr. Martens AirWair FOUNDATION

Young People's Counselling Service

We know that living with ME can be hard and it can leave you feeling **isolated** and **frustrated**.

We're here to help

About the service

- It's **free!**
- For young people **aged 11 - 18** with either diagnosed or suspected ME
- Up to 12 sessions (**online**)
- **Talk about anything** you like!

SCAN ME

X's story

Note: names have been changed for anonymity, on request.

X is 16 years old and has had ME for almost two years. Before their diagnosis, they were a sporty teenager and were doing well at school.

Their life changed significantly when they were diagnosed with ME. Becoming ill also had a negative impact on their mental health and they became isolated as a result of having to stop attending school because of their ME.

"I was incredibly active. I loved doing gymnastics and badminton; I was also getting high grades in school and at my acting lessons. It was stressful having that much going on in my life but ultimately I was happy.

Everything ground to a halt. I had to leave school as it just took too much of my energy, gymnastics, and badminton were now completely off the table, as well as acting.

I lost contact with a lot of my friends and my mental health took a massive dip as all my coping mechanisms before ME were to do with physical activity that I could no longer do. It look at least 18 months for me to find a new balance in my life."

In April 2024, we launched our new Young People's Counselling Service. X was one of the first young people to contact the service and was matched with a therapist. They found the sessions very helpful to talk through things that had happened to them previously, and to gain support as they came to terms with living with ME.

"As my life came to a stop, the change brought up things I had gone through in the past but not fully dealt with. These things, despite having happened years ago, were slowing my recovery.

My counsellor, Hannah, was brilliant at listening to my issues without judgement and helped me start to accept my new life with ME. It definitely wasn't immediate, but my attitude towards myself and my life situation started to change to be more positive and accepting, making it slightly easier to help my body get better."

Young People's Counselling Service

On 01 April 2024, we launched our Children and Young People's Counselling Service for children and young people aged 13-18 with either suspected or diagnosed ME. We recruited two counsellors with specific experience of working with children and young people, particularly those with chronic illnesses.

As a result of accessing counselling:

- **100%** felt less isolated.
- **100%** felt empowered following therapy.
- **100%** felt listened to and understood.
- **100%** felt more able to manage symptoms and feelings about ME.
- **100%** felt more able to deal with the day-to-day challenges of living with ME.

We ensured that young people had the opportunity to shape the service through our Young People's Steering Group. The Group met seven times during the first year of the project and valued the opportunity to help support the service.

"It's kind of empowering to have a space (the Steering Group) where we can talk about all that we go through - and it's the opposite of gaslighting - you've had all these bad experiences with professionals - but this is so different."

Our Lead counsellor and counsellors have begun building relationships with the NHS, helping drive referrals from external agencies.

In March 2025, thanks to funding from The Prudence Trust, we expanded the service to include 11- and 12-year-olds.

"There are such long waits for other wellbeing and mental health services for young people and (as we know) such a lack of knowledge and understanding about ME. There are enough challenges being a young person, let alone coping with a chronic illness; so, to be able to talk to someone who understands is invaluable."

Improving care and support for people with ME

Feeling listened to and understood, involved in the planning of treatment, more in control of symptoms, and feeling more hopeful were just some of the impact that holistic Healthcare Services provided for people with ME.

Central to our mission to improve the lives of people with ME, our doctors, physios, counsellors, and multi-faith chaplains provided over 2,500 consultations. We provided 128 bursaries to people to improve access to these much-needed services.

"Validation was immensely important and far exceeded my expectations and I don't just mean that the GP confirmed everything I suspected/knew but booking and communication were all respectful and helpful. The gulf between your service and my parallel NHS experience couldn't have been wider. Thank God, I had found you!"

From our annual Healthcare Services feedback survey, about our Doctor service

Our commitment to quality care and support

We continued to ensure that, through our multidisciplinary approach to healthcare, every individual who accesses our Services receives the support and guidance they need to manage their condition. Each of our Healthcare Services are designed to recognise and serve the individual needs of each person, recognising that ME affects everyone in different ways.

Our Doctor service offers tailored medical advice and support to help people navigate the many challenges and difficulties people with ME face with understanding, diagnosis, and treatment.

Our multi-faith Chaplaincy service helps to reduce the isolation felt by so many people with ME, through offering emotional and spiritual support.

Our Counselling service also provides a safe space to discuss and explore their feelings with a trained professional who understands the impact ME has on people's lives.

Finally, our Physiotherapy service provides expertise and advice to help improve quality of life, providing patients with a sense of control and hope.

We're changing futures

We're increasing funding for high-quality, biomedical research and supporting the next generation of ME researchers to find effective diagnostic tools, treatments, and ultimately, a cure for ME.

Andy's story

Andy has had ME for 45 years and is now housebound, previously having been mildly affected. He is passionate about the importance of ME research.

Andy uses his experience of living with ME to inform and improve research into the condition. This includes acting as co-investigator and member of the Public and Patient Involvement (PPI) Steering Group for DecodeME, the world's largest ME/CFS research study, which is co-led by Action for ME.

He also works with us as a PPI representative on the Genetics Centre of Excellence Partnership Board and our Sequence ME and Long Covid partnership.

"Change is extremely unlikely to happen without research, and so much needs to change to improve the lives of people with ME, and their families, carers, and loved ones.

Action for ME has been absolutely crucial in ensuring people with ME are at the heart of the research that I have been involved in, and has been essential in supporting me in those roles. If we want more research into ME, with patients forming the heart of every study, then I believe supporting Action for ME is an excellent way to achieve it."

Driving change through our commitment to strategic research

£293k

spent on research-related activity in 2024/25*

470+

watched our first Genetics Centre of Excellence webinar

15,579

DNA samples analysed in DecodeME's initial results

*includes staff time on the DecodeME and LOCOME studies, as well as funding for the PhDs and fellowship, alongside working to forge new potential partnerships.

DecodeME

At the time of writing, the initial DNA analysis results from DecodeME, the world's largest ME/CFS study, co-led by Action for ME, have been released.

The analysis has uncovered 8 significant differences in the DNA of people diagnosed with ME, offering the first robust evidence that genes contribute to a person's chance of developing the disease. These results suggest that both the immune system and nervous system are involved in the development of ME.

> **"These results are groundbreaking. With DecodeME, we have gone from knowing next to nothing about the causes of ME to giving researchers clear targets. This brings ME in line with other long-term diseases which have genetic components."**
>
> - Sonya Chowdhury, Action for ME Chief Executive

Whilst these finds are not yet ready to inform treatment or diagnosis, they represent a milestone in ME research and could offer vital clues to the disease's origins and could guide future drug development.

The DecodeME team are now calling on researchers from around the world to access its rich dataset and help drive forward targeted studies into ME, particularly those linked to the 8 newly identified genetic signals.

Sequence ME and long Covid

In December 2024, we launched a new partnership, Sequence ME and long Covid.

The partnership brings together experts from Action for ME, Oxford Nanopore Technologies, and the University of Edinburgh to uncover the root causes of the conditions and to determine whether they are one illness, or an umbrella condition encapsulating multiple conditions.

The research team will utilise Oxford Nanopore's innovative whole genome sequencing technology to look at every location in the 3-billion letter genome, enabling the identification of rare genetic variants - small changes to DNA sequence - and structural variations.

This detailed picture will allow researchers to search for the biological causes of ME and long Covid with unprecedented precision, laying the foundations for breakthroughs in diagnosis and treatment.

The project builds on the DecodeME study and, subject to funding, would be the largest global single-disease long read genetics study, analysing over 17,000 saliva samples from consenting individuals from DecodeME.

A successful pilot phase, completing any-length sequencing of ten individual samples has already taken place and we are actively seeking funding for the sequencing of the first 10,000 participants.

Genetics Centre of Excellence

2024/25 marked the launch of the Genetics Centre of Excellence (GCoE) Partnership Board, co-Chaired by Sonya Chowdhury, Action for ME CEO, and Prof. Chris Ponting of the University of Edinburgh.

In October, the GCoE held its first webinar to provide an update on its latest activities and hear from prominent researchers. Over 70 people joined the webinar live, with more than 400 people watching the recording.

Audrey Ryback, the first recipient of the Clare Francis Postdoctoral Fellowship awarded by Action for ME, also provided an update on her research on ME biomarkers.

The GCoE also drove the PRIME application - a £844k project aiming to build research capacity for ME in the UK. Funding for the study has now been approved and will commence in October 2025.

Windsor Castle research event

We hosted a research event at Windsor Castle in March 2025, bringing together 27 international experts from different sectors to drive global collaboration in ME and long Covid research.

Discussions focused on genetics, diagnosis, and developing treatment and featured a number of presentations from attendees. The event also provided an opportunity to discuss the importance of other post-infectious and overlapping illnesses.

We're changing futures

We amplify the voices and experiences of people affected by ME at a UK-wide policy level, raising awareness and driving change within Parliament.

National Delivery Plan on ME/CFS

In 2022, Sir Sajid Javid, then-acting Secretary of State for Health and Social Care, announced the Government's intentions to publish a cross-Government Delivery Plan on ME/CFS. The Plan would aim to boost research, advance medical education, and improve patients' lives.

Since then, we have worked hard to continue calls on the Government to publish and implement the Plan in full, utilising our Parliamentary Champions, the APPG on ME, and press and media contacts.

In July 2025, following numerous delays, the Plan has finally been published, marking an important step towards recognising the scale and seriousness of ME.

We thank everyone who has worked to produce the Plan and recognise the commitment that many have shown to its publication. This includes the thousands of people from the ME community who used their time and energy to input into the wider consultation.

However, we are firmly of the view that the Plan does not go far enough to create real, positive change for people with ME. In particular, it fails to address our calls for a strategic approach to research investment, lacks ambition, and is absent of meaningful accountability structures.

Whilst its publication is indeed a positive step, we will continue to call on the DHSC and engage through the Task & Finish Group to ensure that further improvements are made.

We remain committed to ensuring that the Final Delivery Plan delivers the positive change for people affected by ME that it set out to create.

Driving action at policy level

We know that in order to create real change at policy level, we need push hard to catalyse it.

That's why we've continued our commitment to growing our Parliamentary Champions network - a group of MPs who have pledged their support to their constituents affected by ME.

As of 31 March 2025, 13 MPs had joined our network and as of the time of writing, this number has risen further to 18.

Our Champions are our 'go-to' individuals when we're seeking to build support for our campaigns within Parliament and beyond. They support us in a number of ways, such as tabling written and oral questions, tabling and supporting debates on ME, sponsoring events in Parliament, and writing opinion pieces for local and national press.

Alongside expanding this network, we have continued to provide joint-Secretariat support to the All-Party Parliamentary Group (APPG) on ME. The Group's inaugural meeting was held in December 2024, confirming Jo Platt MP as Chair.

At its March 2025 meeting, the APPG confirmed its initial priorities for the coming year, focusing on pressing the Government for the full release and implementation of the Final Delivery Plan on ME/CFS, alongside relaunching the Severe ME Enquiry, which was placed on hold following the change of Government earlier in the year.

In addition, the APPG agreed it would hold two joint meetings with the APPG on Long Covid, also Chaired by Jo Platt, recognising the benefit of collaborative working across the two illness groups.

12

question tabled, written by us for MPs

4

new Parliamentary Champions

10

meetings held with MPs

© Sarah Grady

© Sarah Grady

Lee's story

Starting on 4 May 2024, Lee Colligan took on 'A Walk for M.E.' - the challenge of walking the entire West Coast of Ireland and Nothern Ireland, from Kinsale to Carrickfergus.

Lee decided to take on this challenge to raise vital awareness of ME and funds for Action for ME and the Irish ME/CFS Association, in memory of his brother Josh, who tragically passed away in 2023 after becoming severely ill with ME in 2017.

"Undertaking the challenge of walking 2,500km around Ireland to raise funds and awareness for ME while honouring my brother has given me a purpose."

Lee's walk took 64 days and he documented his journey on his Instagram: a journey that included wild camping, breathtaking scenery, and incredible kindness and support from family, friends, and strangers.

Lee has continued his fundraising efforts for both charities and raised over £26,000 to support our work, and over €13,000 to support the Irish ME/CFS Association through 'A Walk for M.E.' alone.

We are so grateful for Lee's amazing efforts and for the generosity of his community.

"I hope to be one of the sparks that can ignite a fire to get this awful illness the support and recognition it deserves. I've seen first-hand how debilitating this illness can be and I want to be a voice for all of them suffering until they get the support they deserve."

You can look back on Lee's remarkable journey on his Instagram account, or on his website.

@a_walk_for_m.e

https://awalkforme.com/

Danny's story

Danny has had ME for over 10 years and has been fundraising for Action for ME since 2020.

Before developing ME, Danny had been studying at the University of Sheffield and had raised over £85,000 for Blood Cancer UK. He subsequently met Prince Charles and received an award at the Houses of Parliament to recognise his achievement.

Much of his fundraising is now done lying on the sofa using his phone at very small intervals and relies on the support of his friends and family.

"In 2020, the pandemic hit. I was terrified that the difficulties faced by ME charities to fundraise would push back the day we found a treatment even further."

This year, Danny raised over £1,500 through a birthday fundraiser, generously asking friends and family to donate to support our work, in place of celebrating his 30th birthday - an impossibility due to his illness.

Danny and his friends also sold tickets for our Winter Raffle, continued promoting ink cartridge recycling schemes, used fundraising platforms, such as easyfundraising.com, each time they shopped, and asked local organisations for support, which all add up.

To date, Danny has raised over £20,000 for Action for ME!

In Spring this year, Danny shared his story and strategies for low-energy fundraising from his sofa in our membership magazine, *InterAction* We hope his story will inspire others to fundraise in this way if they are able.

Danny's fundraising focus is on ME research. He says:

"I know that, ultimately, we need a cure. Without it, the rest of life is destined to be this way."

We want once again to say a huge thank you to Danny for his continued commitment to supporting our work and to raising vital awareness of ME.

Fundraising spotlight

Each year, our incredible fundraisers go above and beyond to support our organisation, raising vital awareness, understanding, and funds for ME.

London Marathon

It was another successful year at the TCS London Marathon, with our amazing team raising over £34,000 to support our work and people with ME. A few members of our team even travelled to London to cheer them on from the grandstands!

Blue Sunday 2024

This year's Blue Sunday tea party for ME raised £40,024 for 21 ME charities across the world, including £2,170 for Action for ME! We loved seeing the ME community come together, and if you took part, we hope that Blue Sunday gave you a sense of community, connection and hope. We are incredibly grateful to Anna Redshaw for her dedication to raising awareness of ME/CFS and funds to support people with ME.

Lucy's sky dive

Daredevil Lucy jumped out of a plane to raise money for us and awareness of ME. She was inspired by her best friend, who became ill with ME at 16. Lucy smashed her fundraising target and raised over £700 to support our work!

Barretts' & Coopers' Wolds family walk

Mike Cooper, and members of the Barrett and Cooper families raised an incredible £4,675 for Action for ME by completing a 12-mile walk. Each family started from separate sides of the Yorkshire Wolds and met at the halfway point.

Mike's daughter-in-law was diagnosed with ME in 2020 and both families decided to organise a fundraising event to raise much-needed funds and awareness.

We are so grateful to Mike, and both families, for their dedication to people with ME and for supporting our work!

A special thank you

Our work simply wouldn't be possible without the kindness and generosity of others.

From all of us here at Action for ME, a special thank you to the following Trusts and Foundations, whose support helps us take action to create positive change for the children, young people, and adults affected by ME.

Ana Leaf Foundation

Annett Charitable Trust

Christopher Laing Foundation

Dr Martens Foundation

Gerald Bentall Charitable Trust

Himat Tanna Charitable Trust

Hospital Saturday Fund

John Swire 1989 Trust

Kelton Charitable Trust

Lillie C Johnson Charitable Trust

Martin Laing Foundation

Patricia Routledge Foundation

Peacock Charitable Trust

Sir Edward Lewis Foundation

Sir James Reckitt Charity

Souter Charitable Trust

The Belstead Ganzoni Charitable Settlement

The de Laszlo Foundation

The PF Charitable Trust

The Prudence Charitable Trust

Tula Trust

W A Handley

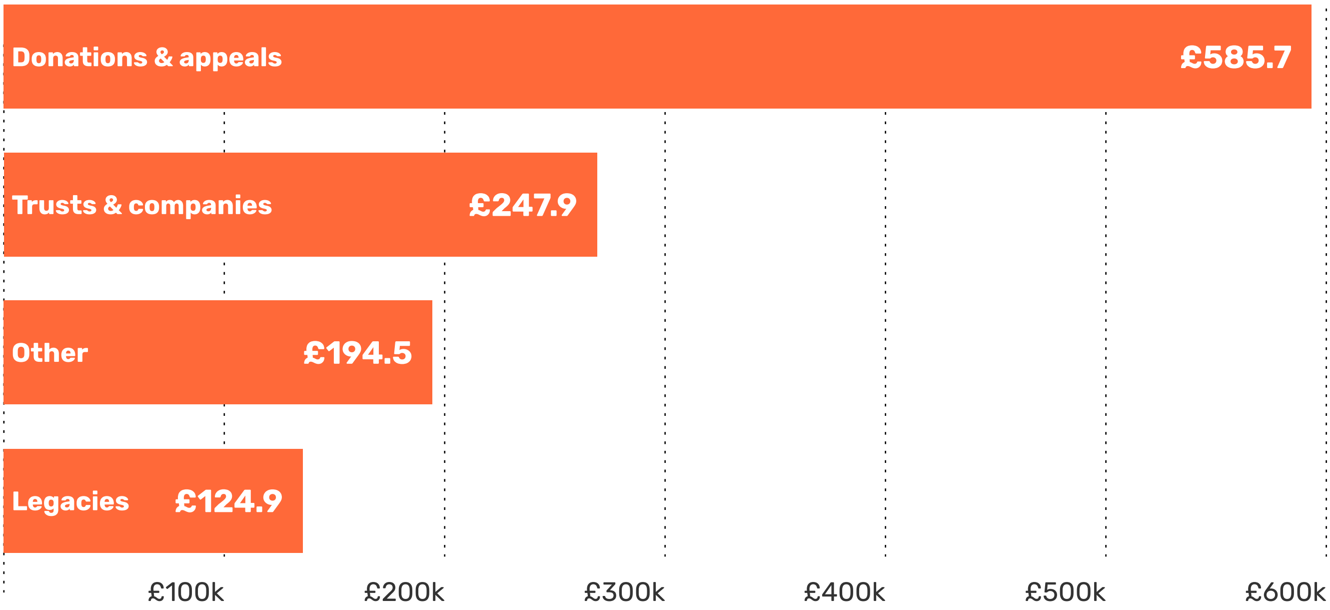
William Allen Young Charitable Trust

Our finances

This year, we experienced a decline in income compared to the previous year, primarily due to the inclusion in the previous year of income from our non-annual 'Breakthrough ME' fundraising dinner and of income from a multi-year grant.

However, in the current year, we took an opportunity to double our target for the annual Big Give Christmas Challenge, successfully raising £276k to support funding towards our existing support and Healthcare Services, Audrey Ryback's research fellowship, and a new medical essay competition. This increased donation income more than offset a reduction in one-off legacies.

Although our income reduced year on year, we decided to maintain our investment in both our people and services which resulted in a deficit for the year. However, our reserves remain within policy.



This year, we spent:

£848k
on our Information and Support, Advocacy, Peer Support, and Healthcare Services for young people, adults, and families with ME.

£419.5k
on fundraising.

£271k
on our investment in collaborative, biomedical research.

£242k
on our campaigning and influencing work.

Summary statement of financial activities

	2025 (£'000)	2024 (£'000)
Incoming resources	1,365.7	1,734.6
Resources expended	1,780.5	1,788.6
Net gains/(losses) on investments	(1.2)	0.3
Net movement in funds	(416.0)	(53.7)
Fund balance 31 March 2025	910.6	1,326.6

Summary balance sheet

	2025 (£'000)	2024(£'000)
Fixed assets	86.1	54.9
Net current assets	824.5	1,271.7
Total assets less current liabilities	**910.6**	**1,326.6**
General funds	397.9	490.8
Designated funds	-	412.8
Unrestricted funds	397.9	903.6
Restricted funds	512.7	423
Accumulated funds	**910.6**	**1,326.6**

Our people, structure and governance

Public benefit

The Trustees confirm that they 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 7-22.

Trustees

The Trustees, for the purposed 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 service 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 ME meets quarterly with the Chief Executive and relevant staff to exercise corporate governance, give strategic direction, and manage the performance and achievement of charitable 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 Manager.

Day-to-day operations are overseen by the Chief Executive, 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 Members.

- 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 are monitored through regular one-to-one meeting 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 for 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 these is a specific 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 ME.

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 2025. 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 ME. This includes other ME charities and patient organisations, health, social care, and government and senior officials, and other decision-makers. As a member of a number of organisations and alliances, including ForwardME, Disability Rights UK, Health Conditions in Schools Alliance, and the Disability Benefits Consortium we continue to build capacity, reach more people, and achieve more by working in partnership to achieve common goals.

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 49. 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 policies

Action for ME 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/UKGDPR 2021, 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 ME 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 honest and integrity, with employees never knowingly misleading supporters. The policy also sets out the way in which we deal with fundraising complaints, of which there were none during the period covered in this report.

Risk

The Chief Executive was 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 to 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 ME. 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 organisation induction policy, with refresher training delivered annually.

No serious incident reports were made to the Charity Commission regarding activity taking place 2024-2025.

Financial review

Statement of financial activity

This year, we reported a deficit of £416k, reflecting our continued investment in charitable activities aligned with our strategic objectives. To support this, £413k of previously designated funds were released, enabling us to sustain momentum in key areas of impact. General reserves at year end were £397.9k.

Restricted reserves were £512.7k (up £89.7k) against last year) which will continue to be expended of the course of next year, on service delivery. We continue to monitor our level of reserves to ensure we can maximise the work we do, whilst also 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 ME predominantly stem from charity trusts, bequests, grassroots fundraising, even revenue, our Supporting Membership scheme, and donations from individuals. Additionally, Gift Aid supplements our fundraising 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.

We are enormously grateful to all the Trusts and Foundations who have generously supported our work this.

Investment policy

Action for ME has an ethical investment policy and when finances allow, aims to invest in line with the values of our organisation. In 2021, the charity invested in the M&G Charibond and an additional £7K this year into M&G Charifund, which, as of March 2025, had a combined net value of £50.5k.

Reserves policy

The current policy is to maintain sufficient funds deemed 'free' (unrestricted) at no less than three times, and no more than six times, the monthly unrestricted operating costs of the charity. The charity ended the financial year with 3.4 months of unrestricted reserves (£397.9k). This is based on an average monthly unrestricted expenditure rate of £115.6k.

Grant making policy

Research funding awards are considered by the Research Subcommittee in accordance with the standards outlined in the Research Activity Ethical Policy Statement. The final decision for award funding sits with the Board.

Statement of Trustees' responsibility

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 a 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. This includes its income and expenditure, of the charity year.

In preparing those financial statements, the Trustees are required to:

- select suitable accounting policies and apply them consistently
- observe the methods and principles in the charity's 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 account records that are sufficient and show and explain the charity's transaction. 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. 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

Sumer Audit Co Limited (previously Moore) were re-appointed as our auditor at the 2024 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 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 special provisions for small companies under part 15 of the Companies Act 2006.

Forward look

In very recent months, we have seen two very significant events for people with ME - the publication of the National Delivery Plan for ME/CFS, and the initial results of the groundbreaking DecodeME research study. The release of the Plan in July 2025 signifies a strong step in the right direction. But we know there is much more to do, and we will continue to advocate for people affected by ME and the need for a strategic approach to research funding within Parliament.

Hopefully, the initial findings from DecodeME will support that approach. It is essential that we capitalise on the momentum the study's successes have created. We aim to achieve this through prioritising fundraising efforts for studies such as Sequence ME and Long Covid, whilst also building on the improved collaboration that now exists within the ME and overlapping illness research fields, thanks to initiatives such as the Genetics Centre of Excellence.

Our Services to people with ME will also be upgraded. Our new online platform provides those who use our Services with more accessible access to the information and support they need, when they need it most. This includes a newer and more accessible ME Friends Online forum.

To achieve our ambitious aims and objectives, we remain focused on improving the effectiveness of our fundraising and have implemented a number of new initiatives to help improve our financial position and invest to give greater results.

I know that with your continued generosity and support, alongside my dedicated colleagues, we will support more people, fund more high-quality research, foster more collaboration and ultimately, make a real impact for all children, young people, and adults affected by ME.

Roger Siddle
Chair,
Board of Trustees

Jonathan Manuel
Trustee and Treasurer

Approved by the Board of Trustees and signed on its behalf on 12 September 2025

Report of the Independent Auditors to the Members of Action for ME

Opinion

We have audited the financial statements of Action for ME (the 'charitable company') for the year ended 31 March 2025 which comprise the 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 (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 2025 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.

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 Auditors' responsibilities for the audit of the financial statements section on 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 other 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 opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the Trustees' use of the going concern basis of account 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 charitable 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 Trustees 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 Report of the Independent Auditors 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 this gives rise to a material misstatement in the financial statements themselves. 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 Report of the Trustees for the financial year for which the financial statements are prepared is consistent with the financial statements are prepared is consistent with the financial statements; and
- the Report of the Trustees has 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 Report of the Trustees.

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate 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 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 take advantage of the small companies exception from the requirement to prepare a Strategic Report or in preparing the Report of the Trustees.

Responsibilities of Trustees

As explained more fully in the Statement of Trustees' Responsibilities, the Trustees (who are also the directors of the charitable company for the purposes of company law) 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 also responsible for accessing 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.

Our 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 a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole 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.

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 to 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, though designing and implementing appropriate responses to those assessed risks; and to respond appropriately to instance 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 company.

Our approach was as follows:

We obtained an understanding of the legal and regulatory requirements applicable to the company and considered that the most significant are the Companies Act 2006, Charities Act 2011, UK Financial Reporting Standards and UK taxation legislation.

We obtained an understanding of how the 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 non-compliance or suspected non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

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. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' 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 and the charitable company's members 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 Sumer Auditco Limited
Chartered Accountants and Statutory Auditor
Lennox House
3 Peirrepont Street
Bath
BA1 1LB

Date: 16 September 2025

Action for ME statement of financial activities

Including income and expenditure account for the year ended 31 March 2025

	Notes	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2025 (£'000)	Total 2024 (£'000)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	621.0	448.6	**1,069.6**	1,198.7
Other trading activities	3	16.2	67.2	**83.4**	335.9
Investment income	4	29.4	-	**29.4**	23.9
Incoming resources from charitable activities	3	183.3	-	**183.3**	176.1
Total incoming resources		**849.9**	**515.8**	**1,365.7**	**1,734.6**
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	362.5	57.0	**419.5**	548.9
Fundraising trading: costs of goods sold and other costs		-	-	**-**	0.1
Charitable activities	5	991.9	369.1	**1,361.0**	1,239.6
Total resources expended		**1,354.4**	**426.1**	**1,780.5**	**1,788.6**
Net (losses)/gains on investments		**(1.2)**	**-**	**(1.2)**	**0.3**
Net movement in funds	12	(505.7)	89.7	**(416.0)**	(53.7)
Reconciliation of funds					
Fund balance at 1 April 2024		903.6	423.0	**1,326.6**	1,380.3
Fund balance at 31 March 2025		**397.9**	**512.7**	**910.6**	**1,326.6**

All incoming resources and resources expended derive from continuing operations. The notes on pages 39-49 form an integral part of these accounts.

Balance sheet

As at 31 March 2025 (company registered number 2906840)

	Notes	2025 (£'000)	2024 (£'000)
Fixed assets			
Tangible assets	9	**2.9**	10.2
Intangible assets	10	32.7	-
Investments	11	**50.5**	44.7
Total fixed assets		**86.1**	**54.9**
Net current assets			
Debtors	12	**291.6**	299.3
Cash at bank and in hand		**615.4**	1,065.9
Total current assets		**907.0**	1,365.2
Creditors: Amounts falling due within one year	13	**(82.5)**	(93.5)
Net current assets		**824.5**	1,271.7
Total assets less current liabilities		**910.6**	**1,326.6**
Capital and reserves			
General funds		**397.9**	490.8
Designated funds	14	**-**	412.8
Unrestricted funds		**397.9**	903.6
Restricted funds	15	**512.7**	423
Accumulated funds		**910.6**	**1,326.6**

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 pages 39-49 form an integral part of these accounts.

Roger Siddle
Chair,
Board of Trustees

Jonathan Manuel
Trustee and Treasurer

Approved by the Board of Trustees 12 September 2025

Cash flow

Action for ME cash flow statement for the year ended 31 March 2025

		2025 (£'000)	**2024 (£'000)**
Net cash flow from operating activities	See note a below	**(437.1)**	(235.1)
Net cash flow from investing activities	See note b below	**(13.4)**	23.9
Net increase in cash and cash equivalents		**(450.5)**	(211.2)
Cash and cash equivalents at beginning of period		**1,065.9**	1,277.1
Cash and cash equivalents at end of period		**615.4**	1,065.9

Cash flows from operating activities

	2025 (£'000)	2024 (£'000)
Net movement in funds	**(416.0)**	(53.7)
Depreciation	**10.4**	9.2
Losses/(gains) on investment	**1.2**	(0.4)
Financial income	**(29.4)**	**(23.9)**
	(433.8)	(68.8)
(Increase)/decrease in debtors	**7.7**	(151)
a (Decrease)/increase in creditors	**(11)**	(15.3)
b Net cash from operating activities	**(437.1)**	(235.1)

Cash flows from investing activity

	2025 (£'000)	2024 (£'000)
Purchase of tangible fixed assets	**(3.4)**	-
Purchase of intangible assets	**(32.7)**	-
Interest received	**29.4**	23.9
Investment in financial assets	**(7.0)**	-
Net cash from investing activities	**(13.4)**	23.9

	At 01.04.2024 (£'000)	**Cash flow (£'000)**	**At 31.03.2025 (£'000)**
Cash at bank	**1,065.9**	**(450.5)**	**615.4**

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 01 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 ME is a private company limited by guarantee and registered in England and Wales. Its registration details are given on p 49. 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 stated otherwise in the relevant account 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 changed 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 with reasonable accuracy. 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, if conditions related to income have not been met or there is uncertainty about whether the charity can meet the conditions, the income is classified as a liability on the balance sheet and is deferred until it is likely that the conditions will be met.

Donated services and facilities (gifts in kind) 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.

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 when 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 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 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 related to its general running, 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 strategic management of the 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 to write off the cost of the assets (less their expected residual value) over their estimated useful economic lives. Office equipments - 25% on the straight-line method.

Intangible assets and amortisation

Towards the end of the financial year we invested in brand improvements which included an upgrade to the Action for M.E website. The expenditure related to the website meets the requirements for capitalisation and has been recognised as an intangible asset. The amortisation period will be a period of 3 years using the straight-line method.

Pensions

The charity operates 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 purposed, 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 £54,153 (£64,192 in 2024).

Operating lease agreements

Rentals, applicable to operating leases when substantially all of the benefits and risks of ownership remain with the lessor are 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 the 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 is 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 2025 (£'000)	Total 2024 (£'000)
Donations and legacies				
Trusts and companies	87.0	153.5	**240.5**	388.9
Donations and appeals	336.9	248.8	**585.7**	383.0
Legacies	124.9	-	**124.9**	271.4
Government grants	-	7.4	**7.4**	32.5
Gift Aid recoverable	43.5	38.9	**82.4**	83.9
Gifts in kind	28.7	-	**28.7**	39.0
	621.0	**448.6**	**1,069.6**	**1,198.7**
Other trading activities				
Events	-	-	**-**	220.3
Lotteries and raffles	7.9	-	**7.9**	8.1
Christmas cards	-	-	**-**	1.5
Supplement commission	2.7	-	**2.7**	3.2
Merchandise	-	0.7	**0.7**	0.8
Other	5.6	66.5	**72.1**	102.0
	16.2	**67.2**	**83.4**	**335.9**
Incoming resources from charitable activities				
Subscriptions	72.6	-	**72.6**	77.4
Healthcare Services	110.7	-	**110.7**	98.7
	183.3	**-**	**183.3**	**176.1**

Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy for work related to contracts and HR advice has been valued at £28,721 (2024: £38,973) based on number of hours worked.

Details of 2024 income

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2024 (£'000)
Donations and legacies			
Trusts and companies	114.2	274.7	**388.9**
Donations and appeals	352.9	30.1	**383**
Legacies	271.4	-	**271.4**
Government grants	-	32.5	**32.5**
Tax recoverable	78.8	5.1	**83.9**
Gifts in kind	39	-	**39**
	856.3	**342.4**	**1,198.7**
Other trading activities			
Events	220.3	-	**220.3**
Lotteries and raffles	8.1	-	**8.1**
Christmas cards	1.5	-	**1.5**
Supplement commission	3.2	-	**3.2**
Merchandise	0.1	0.7	**0.8**
Other	39.5	62.5	**102.0**
	272.7	**63.2**	**335.9**
Incoming resources from charitable activities			
Subscriptions	77.4	-	**77.4**
Healthcare Services	0.4	98.3	**98.7**
	77.8	**98.3**	**176.1**

4 investment income

		2025 (£'000)	2024 (£'000)
Interest from cash investments in the UK		**29.4**	23.9

5 Resources expended

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2025 (£'000)	As restated Total 2024 (£'000)
Costs of generating voluntary income				
Staff costs	256.7	57.0	313.7	235.7
Direct fundraising costs	20.1	-	20.1	97.8
Support costs - see below	85.7	-	85.7	215.4
	362.5	**57.0**	**419.5**	**548.9**

This year we have reclassified fundraising salaries as a staff cost of generating voluntary income where previously the cost has been apportioned across our charitable activities. This is to reflect the accuracy of our fundraising activity and ensure transparency of our fundraising costs. We have applied this method to the previous financial year ending 31 March 2024 for ease of comparison.

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2025 (£'000)	As restated Total 2024 (£'000)
Charitable activities				
Information and Support Services	668.0	180.0	848.0	785.9
Campaigning and influencing work	232.8	9.5	242.3	272.2
Collaborative biomedical research	91.1	179.6	270.7	181.5
	991.9	**369.1**	**1,361.0**	**1,239.6**

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

		Activities directly	Support costs undertaken	As below Total (£'000)
Charitable activity				
Information and Support Services		538.5	129.5	668.0
Campaigning and influencing work		204.9	27.9	**232.8**
Collaborative biomedical research		63.2	27.9	**91.1**
		806.6	**185.3**	**991.9**

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

	Governance costs	Admin costs finance	Property management	Office management	IT admin costs	Total (£'000)
Information and Support Services	20.3	61.2	17.0	21.7	9.3	**129.5**
Campaigning and influencing work	4.3	13.2	3.7	4.7	2.0	**27.9**
Collaborative biomedical research	4.3	13.2	3.7	4.7	2.0	**27.9**
	28.9	**87.6**	**24.4**	**31.1**	**13.3**	**185.3**
Fundraising	13.5	40.5	11.3	14.3	6.1	**85.7**
	42.4	**128.1**	**35.7**	**45.4**	**19.4**	**271.0**

We have reduction in unrestricted overheads by ensuring that eligible costs are appropriately covered by restricted funding, in line with donor intentions and funding agreements. We have also improved cost attribution, allocating more expenses directly to charitable activities, leading to a decrease in overall support costs. Our office relocation during the financial year also contributed to savings.

Office costs include £28,721 (£38,973 in 2024) for professional services in kind.

	2025 (£'000)	**2024 (£'000)**
Governance costs		
Administrative salaries - based on time spent	**27.2**	29.5
Indemnity insurance for Trustees	**1.5**	1.2
Trustee's expenses	**-**	0.3
Auditors' fees	**9.0**	9.6
Design and printing	**4.1**	1.2
Other	**0.6**	0.4
	42.4	**42.2**

	2025 (£'000)	**2024 (£'000)**
Grant activities		
The University of Edinburgh - PhD. in biomedical research	**111.1**	-

Details of 2024 expenditure (as restated)

	Unrestricted funds (£'000)	Restricted funds (£'000)	**2024 (£'000)**
Costs of generating voluntary income			
Staff costs	235.7	-	**235.7**
Direct fundraising costs	97.8	-	**97.8**
Support costs - see below	215.4	-	**215.4**
	548.9	**-**	**548.9**

	Unrestricted funds (£'000)	Restricted funds (£'000)	**2024 (£'000)**
Charitable activities			
Information and Support Services	619.1	166.8	**785.9**
Campaigning and influencing work	266.7	5.5	**272.2**
Collaborative biomedical research	99.2	82.3	**181.5**
	985.0	**254.6**	**1,239.6**

Costs of charitable activities for unrestricted reserves are analysed as follows:	**Activities directly**	**Support costs undertaken**	**As below Total (£'000)**
Charitably activity			
Information and Support Services	333.1	286.0	**619.1**
Campaigning and influencing work	173.9	92.8	**266.7**
Collaborative biomedical research	47.5	51.7	**99.5**
	554.5	**430.5**	**985.0**

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

	Governance costs	Admin costs finance	Property management	Office management	IT admin costs	Total (£'000)
Information and Support Services	18.7	55.6	25.0	157.2	29.5	**286.0**
Campaigning and influencing work	6.1	18.0	8.1	51.0	9.6	**92.8**
Collaborative biomedical research	3.3	10.1	4.5	28.5	5.3	**51.7**
	28.1	**83.7**	**37.6**	**236.7**	**44.4**	**430.5**
Fundraising	14.1	41.9	18.8	118.4	22.2	**215.4**
	42.2	**125.6**	**56.4**	**355.1**	**66.6**	**645.9**

6 Net movement in funds

	2025 (£'000)	2024 (£'000)
This is stated after charging		
Operating lease	**48.0**	38.4
Depreciation of owned fixed assets	**10.4**	8.9
Auditor remuneration	**9.0**	9.6
Trustees' expenses	**-**	0.3
Pension costs	**66.8**	69.4

7 Staff costs and emoluments

	2025 (£'000)	2024 (£'000)
Gross salaries	**909.7**	871.6
Employer's National Insurance	**70.0**	77.2
Employer's pension contributions	**37.4**	29.9
	1,017.1	**978.7**
Average number of employees	**Number (2025)**	**Number (2024)**
Engaged on charitable activities	**22**	24
Engaged on fundraising activities	**9**	6
Engaged on management and administration	**4**	5
	35	**35**
The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:		
	Number (2025)	**Number (2024)**
£60,000 - £70,000	**1**	2
£100,000 - £110,000	**1**	1
Total	**2**	**3**

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 £102,812 (£107,248 in 2024).

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 ME

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.

There were no expenses reimbursed to Trustees or met by the Charity.

There were no expenses incurred by Trustees that were donated back to the Charity.

There were no related party transactions up to 31 March 2025.

9 Tangible fixed assets

	Office equipment
Cost	
At 1 April 2024	51.4
Additions for year	3.4
Disposals in year	(18.1)
At 31 March 2025	**36.7**
Depreciation	
At 1 April 2024	41.2
Charge for year	10.4
Disposals in year	(17.8)
At 31 March 2025	**33.8**
Net book value	
At 31 March 2024	10.2
At 31 March 2025	**2.9**

10 Intangible assets

	Website (£'000)
Cost	
At 1 April 2024	-
Additions for year	32.7
Revaluations in year	-
At 31 March 2025	**32.7**
Amortisation	
At 1 April 2024	-
Charge for year	-
At 31 March 2025	**-**
Net book value	
At 31 March 2024	-
At 31 March 2025	**32.7**

During the year ending 31st March 2025 we commissioned the development of a new website that went live on the 28th March 2025. The amortisation method will be on a straight line basis at an estimated value of £10,917 per year for a period of 3 years. There is no amortisation charge for this financial year.

11 Investments

	£'000
Market value	
At 1 April 2024	44.7
Additions for year	7.0
Revaluations	(1.2)
At 31 March 2025	**50.5**
Net book value	
At 31 March 2024	44.7
At 31 March 2025	**50.5**

There were no investments outside of the UK.

12 Debtors

	2025 (£'000)	2024 (£'000)
Trade debtors	**50.1**	28.0
Prepaid expenses	**35.5**	41.9
Due from HMRC	**2.8**	4.6
Accrued income	**203.2**	224.7
Other	**-**	0.1
	291.6	**299.3**

13 Creditors

	2025 (£'000)	2024 (£'000)
Trade creditors	**32.0**	44.9
Accrued expenses	**22.3**	26.2
Unpaid pension contributions	**6.4**	5.8
Other taxation and social security costs	**18.6**	16.6
Deferred income	**3.2**	-
	82.5	**93.5**

14 Funds

	General funds (£’000)	Designated funds (£’000)	Total (£’000)
Statement of unrestricted funds			
Balance at 1 April 2024	490.8	412.8	**903.6**
Transfer between funds	412.8	(412.8)	**-**
Surplus for year	(505.7	-	**(505.7)**
Balance at 31 March 2025	**397.9**	**-**	**397.9**

	Tangible & intangible fixed assets (£’000)	Cash	Other net current assets (£’000)	Total (£’000)
Analysis of net assets between funds - current year				
Unrestricted funds:				
General funds	86.1	252.8	59.0	**397.9**
Designated funds	-	-	-	**-**
	86.1	**252.8**	**59.0**	**397.9**
Restricted funds	-	362.6	150.1	**512.7**
	86.1	**615.4**	**209.1**	**910.6**

	Tangible fixed assets (£’000)	Cash	Other net current assets (£’000)	Total (£’000)
Analysis of net assets between funds - prior year				
Unrestricted funds:				
General funds	54.9	451.2	(15.3)	**490.8**
Designated funds	-	412.8	-	**412.8**
	54.9	**864**	**(15.3)**	**903.6**
Restricted funds	-	201.9	221.1	**423.0**
	54.9	**1,065.9**	**205.8**	**1,326.6**

In the financial year 2022/23, we received a significant legacy gift, which enabled us to designate funds to support the delivery of our long-term strategic objectives. As these objectives have progressed, we have gradually released portions of the designated funds to support our charitable activities. During the current financial year, £412.8k of these designated funds were released.

15 Restricted funds

	Opening balances (£'000)	Incoming resources (£'000)	Outgoing resources (£'000)	Closing balances (£'000)
Movements in restricted funds				
Research	173.5	135.3	(122.4)	**186.4**
DecodeME	-	57.2	(57.2)	**-**
Services	4.3	199.2	(61.4)	**142.1**
Learn about M.E.	21.4	-	(21.4)	**-**
Breaking Isolation	-	10.3	(8.9)	**1.4**
Children and Young People's Counselling Service	223.8	37.7	(88.3)	**173.2**
Campaigning and influencing	-	9.5	(9.5)	**-**
Philanthropy	-	66.6	(57.0)	**9.6**
	423.0	**515.8**	**(426.1)**	**512.7**

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.

Learn about ME – 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 ME podcast series. Visit https://www.actionforme.org.uk/supporting-you/learning-and-training/.

Breaking Isolation - funding awarded by the Dr Martens Foundation to provide a collection of free online events and resources for young people with ME, designed to reduce the loneliness and isolation often experienced when living with the condition.

Children and Young People's Counselling Service – funding from National Lottery Community Fund to delivery free counselling to young people, aged 13-18 with either diagnosed or suspected ME.

Philanthropy - funded personnel to improve income generation and support long-term sustainability through our philanthropic networks.

All other restricted funding consists of donations received in furtherance of our charitable activities in research, service delivery, and campaigning.

16 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 £6,411 (£5,808 in 2024) were outstanding at the balance sheet date.

17 Operating lease

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

	Total leases 2025 (£'000)	Total leases 2024 (£'00)
Operating lease payments falling due:		
Within one year	**29.2**	39.3
Within two to five years	**87.7**	110.9
Over five years	**-**	-
	116.9	**150.2**

18 Contingent assets

The charity has been advised of a number of legacies which at year end cannot be reliably measured or require grant of probate. These legacies will be recognised as income once evidence of entitlement and the probability of receipt are confirmed.

Legal and administrative details

Action for ME

Registered charity no: 1036419
Registered in Scotland: SC040452
Incorporated on 10 March 1994
Company registration no: 2906480

Registered office

Unit 2.2 Streamline, 436-441 Paintworks
Bristol, BS4 3AS

Bankers

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

Sumer Auditco Limited

Lennox House
3 Pierrepont Street
Bath, BA1 1LB

Trustees and Directors 2024-25

We're improving the lives of people affected by ME. Better meeting their needs today while taking action to secure change for tomorrow.

To donate to our work and help us improve the lives of even more people affected by ME, please visit actionforme.org.uk/support-us/donate

infosupport@actionforme.org.uk

0117 927 9551

Registered 2024/25
FR FUNDRAISING REGULATOR

ACTION FOR M.E.

@actionform.e @actionforme @actionforme @actionforme.bsky.social