ACTION FOR ME

England & Wales · Charity number 1036419

Details

Other names	ACTION FOR M E, AFME
Status	Registered
Legal form	Charitable company
Company number	02906840
Registered	1994-04-14
Register	View on the Charity Commission register

Contact

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Activities

Objects: THE RELIEF OF PERSONS SUFFERING FROM THE DISEASE MYALGIC ENCEPHALOMYELITIS (M.E. WHICH EXPRESSION WHERE USED IN THE ARTICLES SHALL INCLUDE CHRONIC FATIGUE SYNDROMES AND OTHER ASSOCIATED SYNDROMES) AND TO PROVIDE INFORMATION, ADVICE AND SUPPORT AND TO PROMOTE PUBLIC EDUCATION AND RESEARCH INTO THE DISEASE (PROVIDED THAT THE USEFUL RESULTS OF ANY SUCH RESEARCH ARE FULLY DISSEMINATED TO THE GENERAL PUBLIC)

Activities: Action for M.E. was established for the relief of people suffering from the disease MyalgicEncephalomyelitis, (commonly known as M.E., or CFS/ME), and to provide information, advice and support, and to promote public education, campaigning and research into the disease. On a day to day basis we provide telephone support to people with M.E., manage Online M.E Centre and publish 'InterAction'.

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Classification

- **How:** Makes Grants To Organisations, Provides Services, Provides Advocacy/advice/information, Sponsors Or Undertakes Research, Acts As An Umbrella Or Resource Body
- **What:** General Charitable Purposes, Education/training, The Advancement Of Health Or Saving Of Lives, Disability, The Prevention Or Relief Of Poverty, Other Charitable Purposes
- **Who:** Children/young People, Elderly/old People, People With Disabilities, Other Defined Groups, The General Public/mankind

Geography

- Northern Ireland
- Scotland
- Throughout England And Wales

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£1,365,672	£1,780,448	£910,620	35
2024-03-31	£1,734,551	£1,788,660	£1,326,547	24
2023-03-31	£1,123,418	£1,794,518	£1,380,295	40
2022-03-31	£2,497,718	£1,326,158	£2,054,826	29
2021-03-31	£1,192,127	£832,594	£885,515	19

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Trustees

Name	Role	Appointed
Roger Siddle	Chair	2019-10-15
Beatrix Clark		2025-11-26
Colin Morgan		2025-07-03
David Bernard Leigh		2020-11-13
Dominic Hogg		2025-11-26
Dr Nirmala Santiapillai		2022-09-20
Eleanor Jessie Bulmer		2023-09-29
Jonathan Manuel		2021-02-11
Julianne Devine		2022-02-04
Philip Courtney		2022-02-04
Rosalyn Elizabeth Boyle		2024-06-25
Sarah Anderson		2025-11-26
Shaun Vernon De Boo		2021-02-11
Wendy Lippmann		2024-12-05

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ACTION FOR ME

England & Wales - Charity number 1036419

Accounts

Action for ME

Annual report and accounts

2024/25



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

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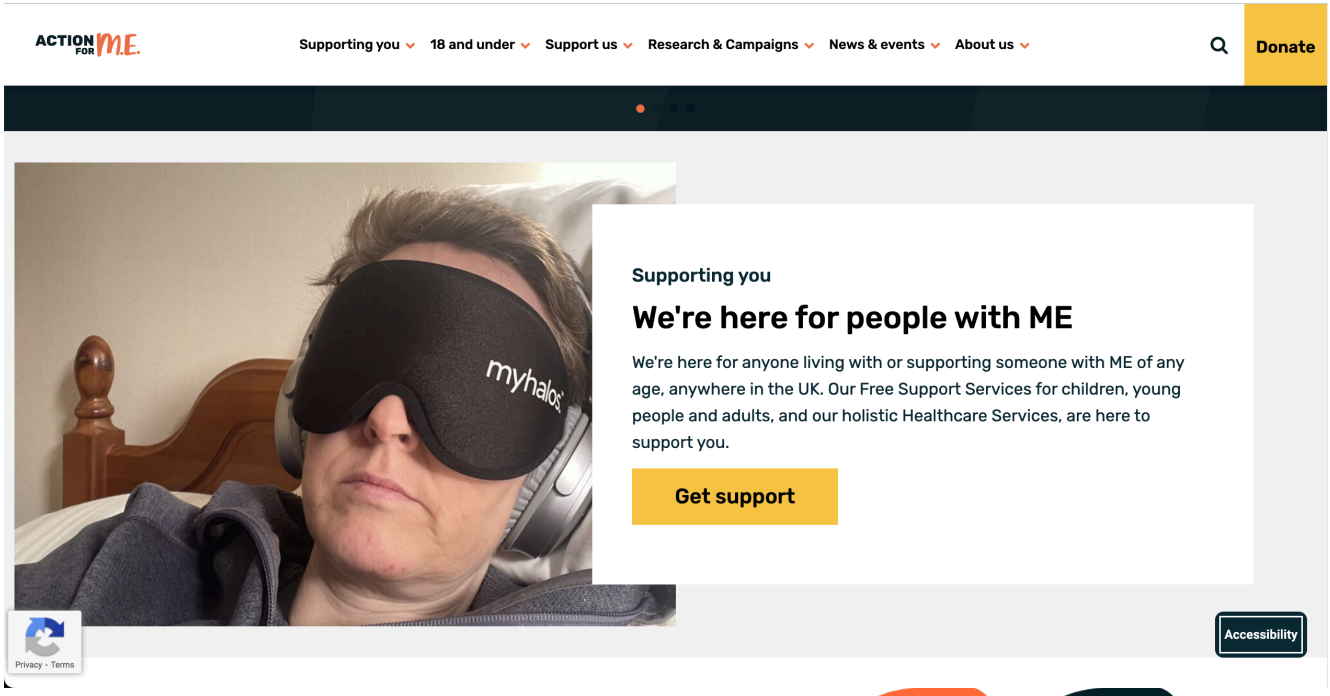
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Investing for the future



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
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
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

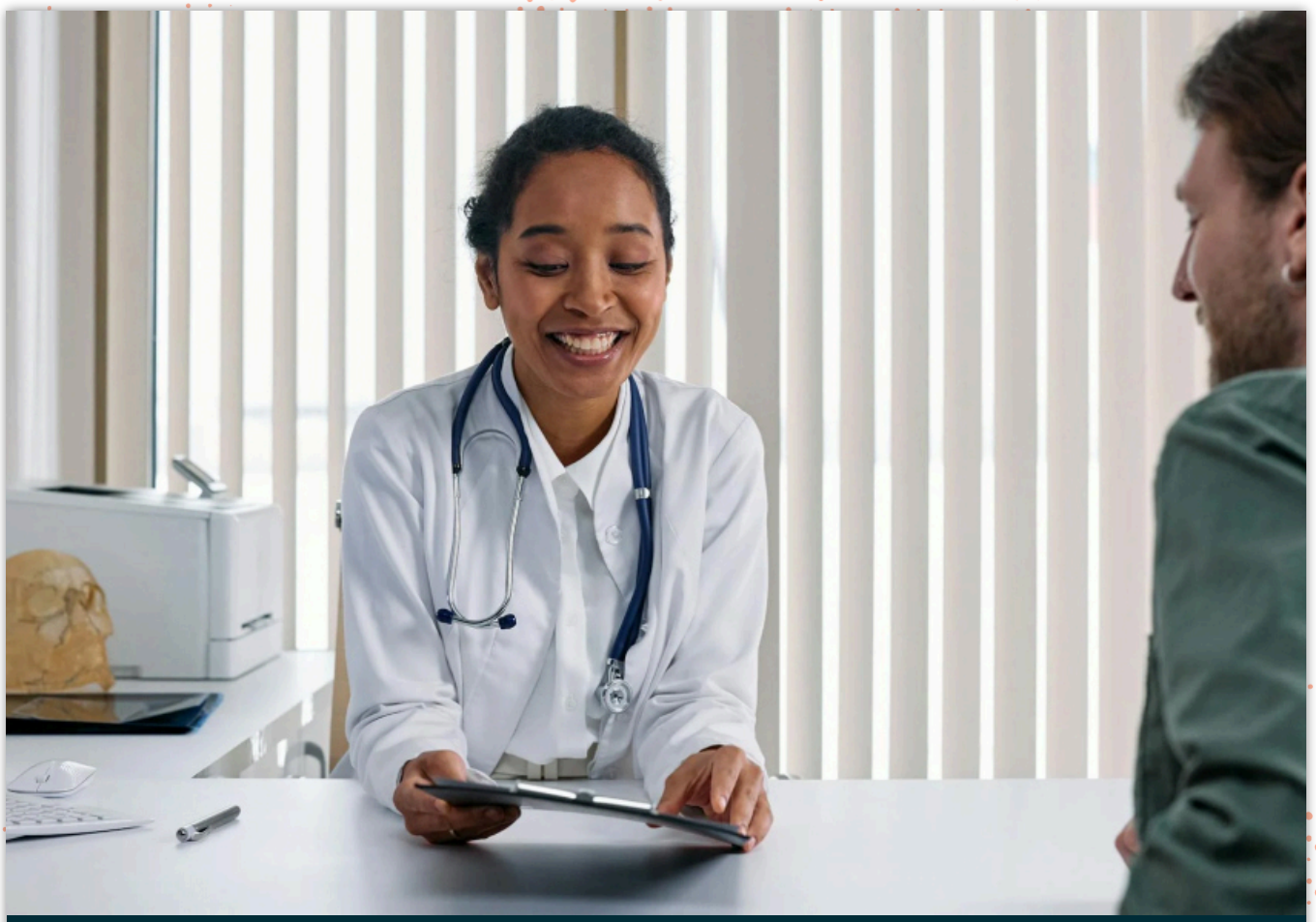
The essay competition saw nearly 30 entries from students across Scotland. In 2025, thanks to our Big Give Christmas Challenge Campaign, we are taking this competition nationwide.

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. AirWair Martens 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

SCAN ME

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!

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:



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



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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

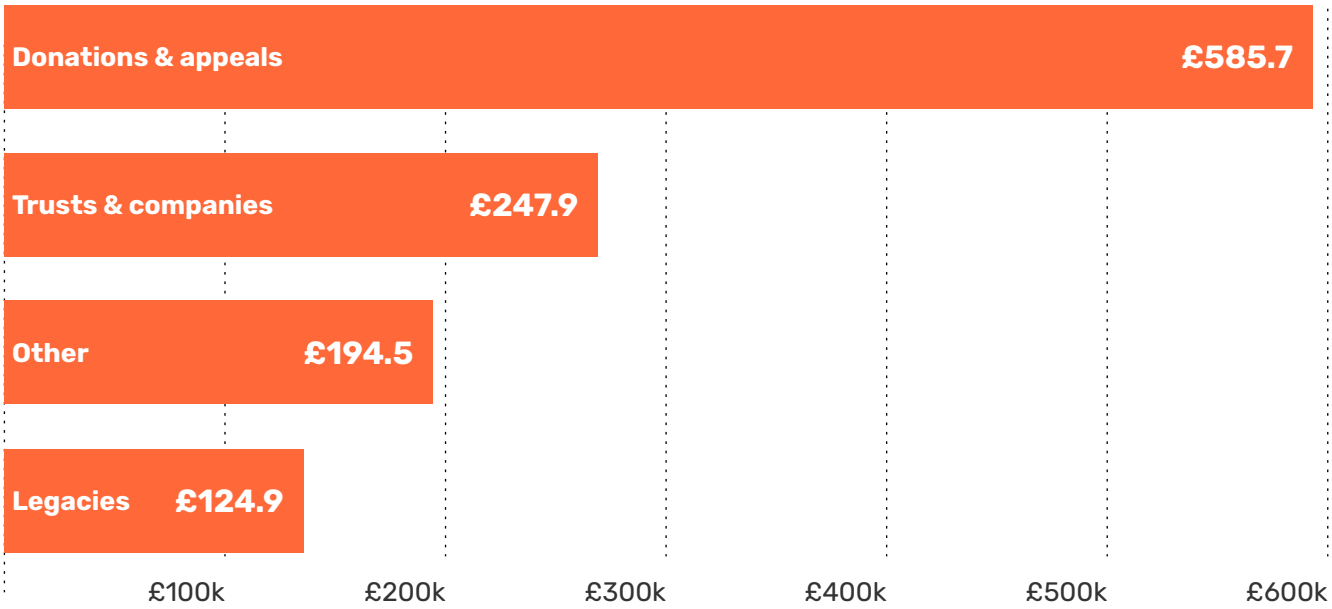
William Allen Young Charitable Trust

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.

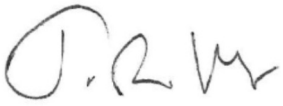
Our Services to people with ME will also be upgraded. Our new online platform provides those who use our Services with more accessible access to the information and support they need, when they need it most. This includes a newer and more accessible ME Friends Online forum.

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

President
Clare Francis MBE

Vice President
Martin Arber

Patrons
Lord Bragg
Julie Christie
Lord Puttnam CBE
Alan Cook CBE
Prof Anthony J Pinching
Sarah Dorin
Philip Mould

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Ondine Upton

Board Advisor
Denise McLellan

Board of Trustees
Roger Siddle, Chair
Jonathan Manuel, Treasurer
Philip Courtney
Shaun De Boo
Julianne Devine
Sue Hardy
Rollo Hope (stood down February 2025)
David Leigh
Nirmala Santiapillai
Eleanor Bulmer
Jeff Banks
Wendy Lippmann (joined December 2024)
Ros Boyle (joined June 2024)
Colin Morgan (joined July 2025)

Chief Executive
Sonya Chowdhury

Principal Medical Advisor
Prof David Strain

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 FUNDRAISING REGULATOR

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ACTION FOR ME

England & Wales - Charity number 1036419

Accounts

action for m·e

Action for M.E. Trustees' report

2023 - 2024





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Cover image: Artwork by Maya & Ink, who has ME
@maya_and_ink

CEO's message

There are now an estimated 1.3m people in the UK with ME or ME-like symptoms, including post-exertional malaise, with this number likely to increase further as the full impact of long Covid becomes present.

That's why we're acting now to provide vital support and care to people with ME today, whilst driving positive change for the future.

Despite the increasing demand on our Services and the increasing complexity of the cases, we have continued to be a "lifeline", providing support for so many people, families and carers affected by ME and I'm so proud of what we have achieved as an organisation in such a challenging environment.

From April 2023 to March 2024 our Information and Support service exchanged nearly 2,000 calls, emails, texts, and direct messages on social media with people affected by ME. Through dedicated and caring support, 96% said they were either satisfied or very satisfied with the service they received, demonstrating the incredible work of my colleagues and the impact that it has for people affected by ME.

We have been pleased to see our Healthcare Services go from strength to strength, with over 1,900 consultations provided to almost 850 people with ME. This has ensured they can access holistic support, tailored to their specific needs, whilst there remains a significant absence of specialist service provision available elsewhere. During the year, we worked hard to reduce waiting lists to ensure that people with ME can access the support they need, when they need it. Whilst waiting lists for our Doctor service have risen, we are hoping a new doctor will start imminently, reducing wait times once again.

We have continued to accelerate high-quality research in the ME field and I am delighted that we were able to announce the £622,000 LOCOME study, awarded by Innovate UK's Advancing Precision Medicine programme, to improve diagnosis and treatment for the millions of people affected by ME/CFS and long Covid.

In August 2023, DecodeME published initial findings from the first questionnaire data, collected from the first 17,000 participants. This publication was picked up by numerous news outlets, amplifying the important findings and generating further awareness of the groundbreaking study. The study has regretfully experienced delays due to operational and capacity issues at the UK Biocentre, causing DNA extraction to take longer than anticipated. However, colleagues are working hard to ensure the analysis and subsequent findings remain robust, and we look forward to sharing further updates on the study soon, with the project completion date now extended to August 2025.

Last year brought the exciting news of the Government's plans to develop and publicise a cross-Government Delivery Plan on ME/CFS for England, aligning with other devolved nations as appropriate.

We were pleased to see the Interim Plan published and the consultation receive an overwhelming response from the ME community, highlighting the importance and need for the full Plan. However, it is still yet to be published, with further delays leaving people with ME without appropriate support; without hope that things will change for the better. We remain committed to ensuring the Plan is published and implemented in full, now with support from our new Parliamentary Champions Network – a committed network of MP's dedicated to advocating for people with ME within Parliament – and welcomed the Labour's commitment to publishing the full Plan in Winter 2024/25.

We have also continued to work closely with the All-Party Parliamentary Group (APPG) on ME, ensuring the voices and experiences of people with ME are heard within Parliament. Whilst the departure of Carol Monaghan as Chair comes with great sadness, we are excited to continue the work of the APPG and look forward to working to improve its communication and collaboration with the ME community.

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
Chief Executive
Action For M.E

Chair's message

We believe real change doesn't just happen. It's made. That's why action and impact are at the heart of everything we do, as we pursue positive impact for the lives, rights and futures of people affected by ME.

We therefore position ourselves at the intersection of direct support and long-term change, with our strategy having four main pillars:

Direct support - helping people today with information and support

Sadly, the impact of long Covid continues to grow, with ever-increasing numbers of people reporting symptoms that mirror those of ME and demand for our Services remaining high. Despite these challenges, my colleagues here at Action for M.E. have continued to support growing numbers of people affected by ME through complex issues.

Direct support - providing healthcare services directly to those who need it

Our Healthcare Services are progressing well, providing holistic support to over 840 people with ME from April 2023 to March 2024, with waiting lists now lower than this time last year due to the hard work and dedication of colleagues. Whilst challenging, we are building experience in attracting and retaining doctors to support the service and are hopeful this will become less of an issue.

Long term change – seeking to accelerate breakthrough research

Whilst we share in the disappointment surrounding the delays and extension of the DecodeME project, we have been encouraged and overwhelmed by the ongoing involvement of people with ME in the study and remain committed to ensuring the study delivers the greatest impact it can for people with ME.

We have also seen some vitally important and exciting research updates, including our announcement of the launch of the LOCOME project, aiming to improve diagnosis and treatment for those affected by ME/CFS and long Covid, and the first Clare Francis Research fellowship to Audrey Ryback, who will be affiliated to the Genetics Centre of Excellence at the University of Edinburgh. You can read more on these important projects on p 10-11.

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

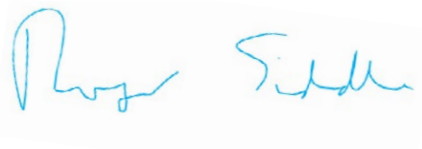
We remain proud of our work, alongside others, in helping to initiate the Government's development of the National Delivery Plan for ME/CFS. Like you, we have been frustrated at the continuing delays to its publication. We therefore welcome the announcement by the new Government to publish the Plan no later than the end of 2024 and hope that this will mark the beginning of a significant shift in attitude and action at the highest levels to support people with ME.

It was encouraging to see the high levels of engagement of MPs in the prior Parliament with the All-Party Parliamentary Group (to which we provide joint-secretariat support), and to see the successful launch of our Parliamentary Champions Network, a group of MPs committed to working alongside us to generate much needed awareness and understanding of ME within Parliament. With the significant changes of membership in the new Parliament, our focus now moves to replicating this success in the new parliament, ensuring that the voices of people affected by ME are not lost.

Why can we not do more? Our answer is regrettably simple – 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 £1.7m. Despite this relative success, our income must remain a priority to deliver on our goals – and if we had more, we could do more or go faster.

The world for people with ME is often beset by enormous challenges and frustrations, and I would like to thank my colleagues for their vital contributions to the ongoing work that I have outlined and, most of all, for their dedication to supporting and improving the lives of people with ME.





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

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



Our free Support Services empower children, young people, adults and carers to address the significant challenges that life with ME can bring. Responding to nearly 2,000 new requests for support this year, we offer the understanding and support that can be hard to find elsewhere.

"You said you'd fight for me and you did, especially when I felt so many times defeated […] I have never felt more genuinely supported." Ounissa, we worked with to successfully challenge her housing association's unfair decision.

From helping parents secure the right support at school for their child, to seeing that child make friends in our safe and secure online forum; from supporting someone to self-advocate at their GP appointment, to signposting that GP to CPD learning resources on diagnosing and managing the condition, we stand with people with ME to improve their lives.

We continued to use client feedback to inform and improve all our Services, and we are exploring more accessible ways to ensure those with severe ME and from underserved communities have access to resources and information in the way that works for them.

We want to do even more. In response to the needs of those we support, we have relaunched our independent Adults Advocacy service. Thanks to generous funding from the Dr Martens Foundation, we have also extended our Breaking Isolation series of online workshops, where young people with ME can make friends and share how they live with the condition.

As a result of contact with us:

98%
of Family Support clients said they felt more confident communicating with professionals

90%
of our Young People's community members said their wellbeing had improved

84%
of Information & Support clients said they had increased understanding of rights and options



Supporting ‘Newbutnotnew’

Thank you to Newbutnotnew, who asked to use their ME Friends Online forum username as a pseudonym, for sharing their experience in this report.

Newbutnotnew first contacted us when she had been signed off work for two months with persistent and severe fatigue: “When I unwittingly overdo physical and/or mental activity, I go downhill again. GPs ran blood tests, all clear. I know this is too early for a diagnosis of ME I just want to make sure that I am informed and accessing the right guidance.”

Armed with the NICE guideline and Action for M.E.’s guide to pacing – an approach people with ME/CFS use to track and manage their precious energy – Newbutnotnew started keeping a diary of her symptoms and activity.

“It helped me see and establish patterns with my sleep and begin to practice therapeutic rest. This gave me confidence and data to communicate with GPs and my employer during long-term sick leave.”

Newbutnotnew joined our ME Friends Online forum, finding a friendly community and an invaluable source of insight and shared experience.

“The practical and emotional support of the forum has kept me afloat, helped with periods of intense fear and helplessness, and been brilliant inspiration for pacing and creativity.”

When Newbutnotnew got back in touch some months later because she was struggling to find her baseline activity level, a crucial element of pacing, our Information & Support Officer Juliet (pictured) talked through possible options in detail. Newbutnotnew chose to take up a referral to our Healthcare Services team (see p8-9) for physiotherapy support while she pursued a diagnosis and found this “so incredibly helpful” in helping her pace more effectively.

Newbutnotnew told us that its the breadth and consistency of the sort of personalised support and understanding she was able to access through our range of services – “the opposite of one size fits all” – that have made such a significant difference.

“I cannot even begin to imagine what this experience would have been like without Action for M.E. I know for certain I would have suffered a great deal more and almost certainly become more ill. I am immensely appreciative of this service, the forum and Juliet’s help.”

Dr. AirWair Martens
FOUNDATION

“I am immensely appreciative of this service, the peer support forum and Juliet’s help”

The health of people with ME is improved via access to our holistic Healthcare Services

Healthcare services provision: transforming lives with compassionate & tailored care

Our Healthcare Services are central to our mission to improve the lives of those affected by ME. We recognise the significant challenges that living with ME presents, which is why we are committed to providing holistic, patient-centred care that is compassionate, accessible, and informed by the 2021 NICE Guideline on ME/CFS.

In the past year, our Healthcare services have supported 847 individuals, offering 1,940 patient consultations.

Over 40% of these individuals received bursary support from Action for M.E., ensuring that financial barriers did not prevent access to the care they needed.

We were also able to extend our reach, welcoming 239 new patients into our services, demonstrating our ongoing commitment to supporting the ME community.



Our commitment to quality care

We take pride in our multidisciplinary approach to healthcare, ensuring that every individual receives the support and guidance they need to manage their condition. Our multi-faith Chaplaincy, Counselling, and Doctor services are designed to meet the unique needs of each person, recognising that ME affects everyone differently.

Our Counselling service provides a safe space for individuals to explore their feelings and challenges with trained professionals who understand the complexities of ME. Our Chaplaincy service offers emotional and spiritual support to those who may feel isolated due to their illness.

Meanwhile, our Doctor service connects patients with specialists who can offer tailored medical advice and support, helping them navigate the often-challenging path to diagnosis and treatment.

Looking forward: expanding our reach

As we move forward, we remain committed to expanding and enhancing our Healthcare Services. We recognise the growing need for accessible, high-quality care for those living with ME, and we are determined to do even more.

Whether it's through expanding our services, increasing the availability of bursary support, or continuing to advocate for better healthcare policies, we are here for everyone affected by ME.

Together, we can make a difference in the lives of those with ME, offering hope, understanding, and the compassionate care they deserve.

Patients' stories

In 2023-24 alone:

94%
of people who used our Doctor service said they felt listened to and understood

89%
of people who spoke to one of our Counsellors reported the service had a positive impact on their emotional health

85%
of people who used our Physio service said they felt involved in the planning of their treatment

Frances's Story: The Doctor service

Frances, another service user, emphasised the profound impact our Doctor service has had on her journey with ME.

"The appointment was brilliant. For the first time in two years, I feel that someone actually understands and is listening to me. Plus, he is able to make research-based suggestions to my GP which will hopefully make a real difference. I can't thank the organisation enough for making this possible," Frances shared.

Frances' experience underscores the importance of having access to knowledgeable and empathetic healthcare professionals who truly understand ME.

Jan's Story: The Counselling service

Jan has also found immense value in our support services, particularly the Counselling service.

"You have all been absolutely amazing and I am very grateful for this organisation. I felt lost and alone and very confused when I first reached out for advice. I had two phone calls which were so, so helpful, I felt listened to and valued. There were amazing follow up emails with all the information I needed, and even helpful hints about taking it slowly. [My counsellor is perfect] for me and I look forward to the sessions. She listens and gives me space to talk but she's also super engaged and I value her knowledge and understanding. So glad I found you."

Jo's Story: The Chaplaincy service

For Jo, the Chaplaincy service has been a lifeline. She shared:

"Talking to an Action for M.E. chaplain has been a blessing to me. A real lifeline as I can't go to church and rarely have visitors. My chaplain is a kind and compassionate person. He's a good listener who doesn't judge. It's always a pleasure to talk to him. I trust him completely. Moreover, [he's] made the process accessible to me – a severe ME sufferer. I recommend the Chaplaincy service. Don't be afraid to give it a go."



Increased funding for high-quality research by more researchers leads to effective treatments for ME services



In 2023, DecodeME published initial findings from the first questionnaire data, collected from the first 17,000 participants, with findings revealing that women with ME/CFS tend to have more symptoms and co-occurring conditions than men. It also showed that women who have ME/CFS for more than 10 years are more likely to experience increasingly severe symptoms as they age.

We were pleased to work with DecodeME colleagues and a number of mainstream news outlets to amplify the important findings and generate further awareness of the groundbreaking study.

Decode ME
The ME/CFS Study

Long Covid and Myalgic Encephalomyelitis diagnostics and stratification (LOCOME) project

In December 2023, we announced a new partnership with PrecisionLife and the University of Edinburgh to deliver a £622,000 innovative precision medicine project to improve diagnosis and treatment for people with ME/CFS and long Covid. PrecisionLife will perform combinatorial analysis on long Covid datasets and the DecodeME data.

In 2023-24, we spent

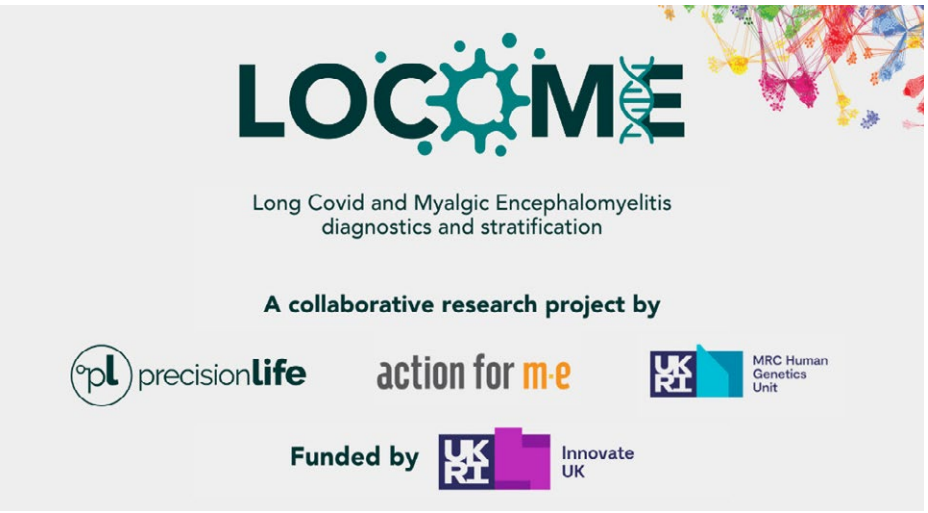


£203,287
on research-related activity*

*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

Using its precision medicine and mechanistic patient stratification approach, PrecisionLife aims to identify the factors driving disease in different patient subgroups.

The insights and biomarkers that this generates will be used to create the first predictive diagnostic tools to rapidly triage people presenting with potential ME/CFS or long Covid symptoms and identify novel repurposing opportunities to accelerate access to disease modifying treatments for patients.



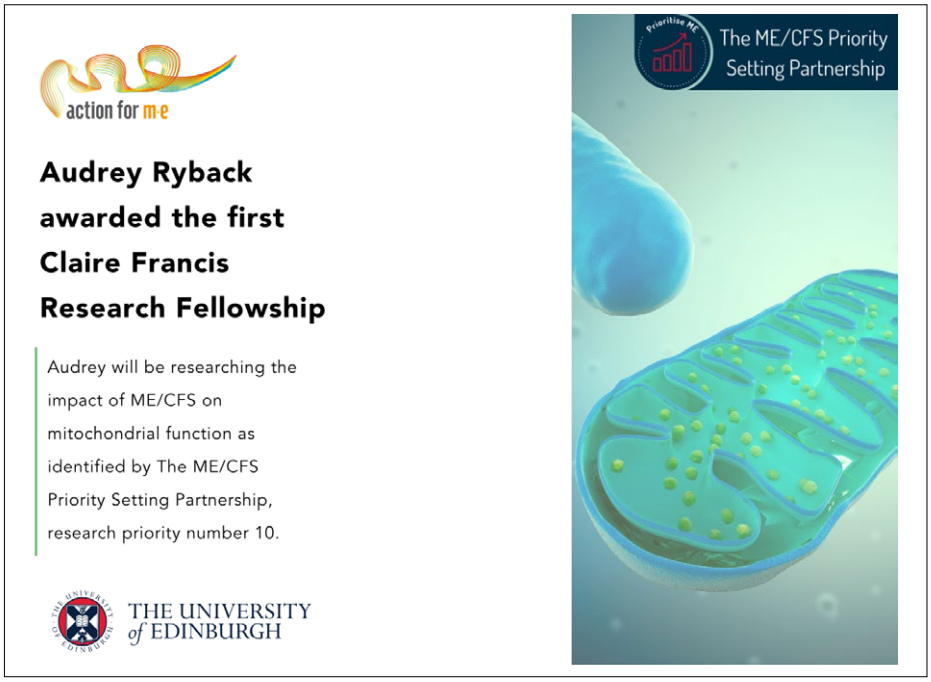
Clare Francis Fellowship

The first ever Clare Francis Fellowship of £147,000 was awarded to the University of Edinburgh for Audrey Ryback. Audrey is affiliated to the Genetics Centre of Excellence which we are delivering in partnership with the University of Edinburgh, with Professor Chris Ponting supervising the 2-year fellowship.

Audrey is researching the impact of ME/CFS on mitochondrial function as identified by The ME/CFS Priority Setting Partnership, research priority number 10.

Considerable scientific evidence suggests that the way in which energy is produced and used by cells within the body is abnormal in those affected by ME/CFS. Therefore, the role of mitochondria, the cellular "powerhouses", in this condition is recognised as a priority for further research.

"The first Clare Francis Fellowship of £147,000 was awarded to the University of Edinburgh for Audrey Ryback"



Audrey's research project will try to identify and characterise factors in the blood of patients that may be responsible for disturbing their mitochondria. Equally important, if Audrey can show that such a factor exists, this could provide a meaningful and easy-to-measure diagnostic test for ME/CFS, for which none currently exists.

Audrey is making great progress with her research being delivered on time with a new partnership with Sheffield Hallam University and she has already secured additional funding to build out her research.

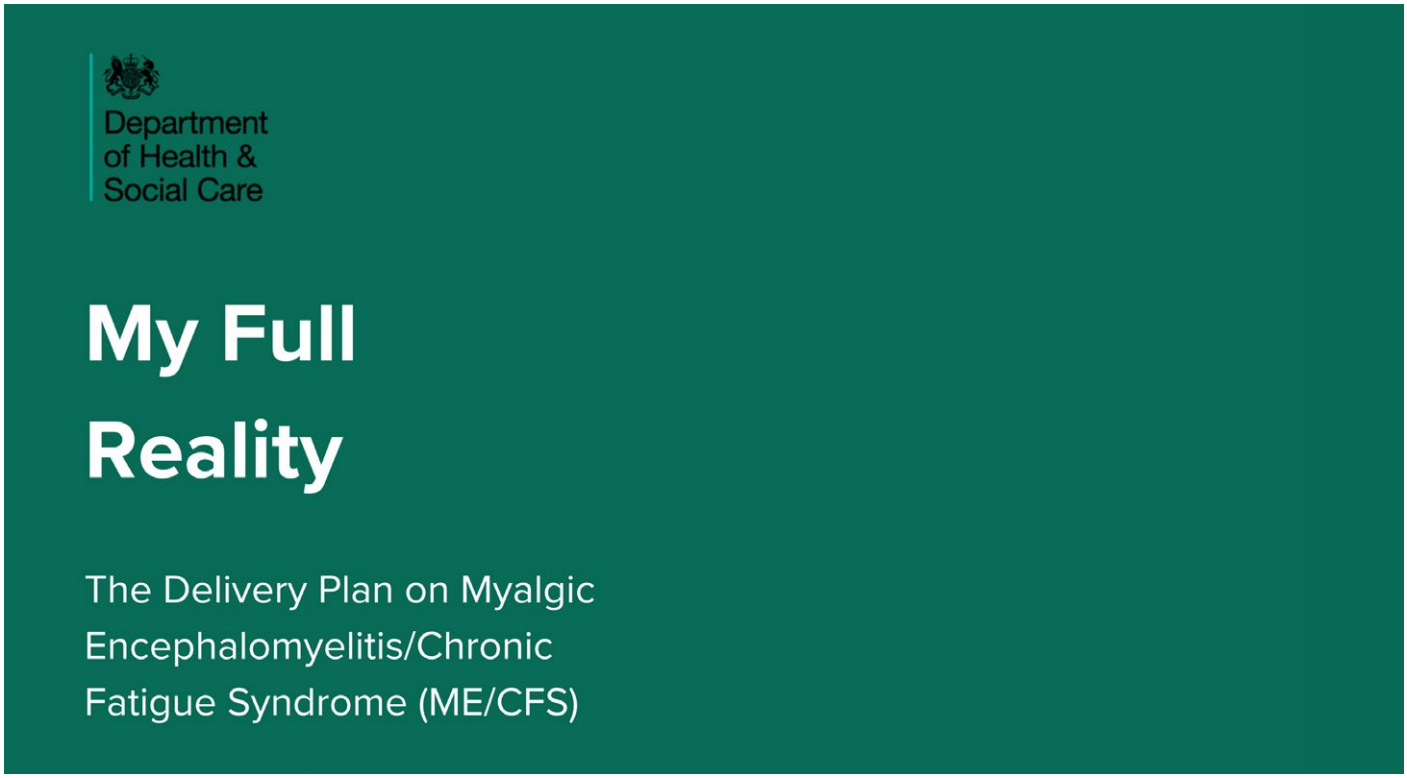
ME Genetics Centre of Excellence

We continued work on establishing the ME Genetics Centre of Excellence in partnership with the University of Edinburgh and established a Partnership Board of people with lived experience of ME, researchers, and a representative from the Future Leaders' Network, ensuring that the invaluable views and experiences of people with ME remain at the heart of our work. During the year, we worked to embed the Board and work towards developing our plan for the future.

Research Working Group

We contributed to the Research Working Group of the Government Delivery Plan on ME/CFS, leading to the Interim Plan being launched and with further work continuing beyond this to progress actions identified.

The UK Government establishes and leads a national strategy for ME



National ME/CFS Delivery Plan

In August 2023, the Department for Health and Social Care (DHSC) published its Interim Delivery Plan on ME/CFS, alongside a focused 8-week consultation.

The community responded in force, with over 3,500 received from individuals with ME, carers and family members, from professionals and organisations working in the ME field.

Referencing the high number of responses to the consultation, the full publication of the Plan was yet again delayed, causing frustration and concern from the ME community, with the Plan now expected, at the time of writing, during Winter 2024.

We remain committed to ensuring the Government fulfils its promise of the full publication of the Plan, and the commitments it makes to people affected by ME.

FOI report

On 30 May 2023, we published our Freedom of Information (FOI) report into the 'Implementation of the NICE Guideline [NG206] on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome in England'.

The report revealed that people with ME are dealing with shockingly poor and patchy provision of services in England:

- Only 28% of NHS Trusts and ICBs have implemented the 2021 NICE guideline.
- Fewer than one in four NHS Trusts and ICBs are able to track their ME/ CFS patients.
- Two thirds of NHS Trusts and ICBs hold no information whatsoever on their ME/CFS patients.



Following the publication of the report, we engaged with MPs, Ministers and press to share the findings and clearly demonstrate the unacceptable levels of service provision that exists for people with ME in England.

Disability White Paper

The Government launched their 'Transforming Support: The Health and Disability White Paper' in May 2023.

As with many others within the ME community, we shared concerns regarding the Work Capabilities Assessment and the need for it to better-reflect the needs of people with ME.

Working with Fleur Anderson MP, a member of our Parliamentary Champions Network, our Head of Services, Clare Ogden, met with Tom Pursglove MP, the then-Minister for Disabled People, Health and Work to discuss these concerns, ensuring the voices and experiences of people affected by ME were heard as part of the Paper's consultation.

ForwardME

Throughout the year, we continued to work in collaboration with other ME organisations as a member of ForwardME, including ongoing engagement with the DHSC regarding the Delivery Plan.

All-Party-Parliamentary Group on ME

We continued to provide the Secretariat for the All-Party Parliamentary Group (APPG) on ME, co-funded by the ME Association, which included a specific focus on severe ME and preparation for an APPG-led inquiry into severe ME.

The inquiry was unfortunately stopped when the election was announced, but we look forward to reconstituting the APPG and launching a new communications strategy for it, ensuring a level of transparency and improved engagement with the ME community.

Parliamentary Champions Network

In December 2023, we unveiled our new Parliamentary Champions Network; a group of 'go-to' MPs and Peers for engaging with Government and building support for our campaigns more broadly in Parliament and beyond. Prior to the 2024 General Election, 7 dedicated MPs were part of our network and we look forward to expanding its numbers and influence as we move forwards.



Fleur Anderson MP | Carol Monaghan MP | Debbie Abrahams MP

This network of dedicated Champions is essential for raising awareness of ME, helping to include ME and related issues in parliamentary business and working with the media. Our Champions also assist by tabling written and oral questions on ME, sponsoring events in Parliament, and writing opinion pieces for local and national press.

"As Chair of the APPG on ME, I am thrilled to become a Parliamentary Champion for Action for M.E. and I stand committed to raising awareness, driving research, and fighting for greater support for those whose lives are affected by this often misunderstood and debilitating condition." – Carol Monaghan, then-MP for Glasgow North West.

Connect

Connect Public Affairs have worked with us over the past few years to enhance our public affairs work and ensure we further amplify the needs of people with ME, with policy/decision-makers and the press and media.

This has been an important investment which has contributed to increasing engagement with parliamentarians, and resulted in us launching vital initiatives, such as our Parliamentary Champions Network.

Additionally, we have seen an increase in our engagement with the press and media. As an organisation with a small team, the additional capacity, expertise, and established relationships that Connect colleagues bring to our work, has created real value in helping us deliver against our ambitions.

Year in numbers



85%
of children and young people said they feel less isolated after accessing our Children and Young People's Community



Over 1,900
consultations provided to people with ME through our holistic Healthcare Services



1,133
The number of articles we were featured in throughout the year, raising vital awareness of ME



Thousands of people with ME stayed connected with others through our friendly and safe Forums

"Just thanks for listening, taking me seriously and understanding, it's really appreciated."

"Informative, empathetic and understanding of the issues raised relating to ME as this impacts our son and the family"



96% of people
who used our Info & Support service said they were satisfied or very satisfied with the support they received



100%
of users of our Family Support service said they feel in a stronger position to support their child



£119,900
raised in our 7th Big Give Christmas Challenge



26,000
responses were received to the first DecodeME survey

A special thank you

Once again, we would like to say a huge thank you to our donors, funders, fundraisers, supporters and volunteers. Without your support, we would not be able to continue our work in supporting people with ME now and creating positive change for the future – this section is dedicated to you.

Our volunteers

Volunteers are integral to our work and without them, we wouldn't be able to produce our *InterAction* magazine, moderate our peer-support forums, or write Birthday and Christmas cards for people with ME. Thank you so much to you all for everything you do to support us.

Our staff

Colleagues have once again demonstrated their unwavering commitment to supporting the children, young people, and adults with and affected by ME. Despite wider external pressures and uncertainty, you have continued to deliver value above and beyond, with the positive impact this has on the lives of people affected by ME, clear to see. Thank you

Blue Sunday

Champion fundraiser, Anna Redshaw's 'Blue Sunday' fundraising event raised over £36,000 for ME charities across the world, including more than £7,500 for Action for M.E. We cannot express our gratitude enough to Anna, for her commitment and dedication to raising funds for people with ME and raising vital awareness and understanding of the condition at the same time.

Our 2023 Marathon runners

It was another incredible year for our marathon runners, with our Edinburgh and London Marathon teams raising over £43,000 to support our work. Thank you to you all.

Partnering organisations

Thank you also to the other organisations we work closely and in partnership with, without whom, we would not be able to continue to provide our important services or accelerate change for people with ME.

A special thank you to our funders:

Anna Leaf Foundation

One Gloucestershire Integrated Care System

Christopher Laing Foundation

Doris Field Charitable Trust

Eveson Charitable Trust

Gerald Bentall Trust

Hugh Fraser Foundation

Johnsons Group Cleaners Charity

National Lottery Reaching Communities

One Gloucestershire Integrated Care System

Peacock Charitable Trust

Scottish Government

Sir Edward Lewis Foundation

Sir James Reckitt Charity

The de Laszlo Foundation

The February Foundation

The Kelton Trust

The P F Charitable Trust

The Patricia Routledge Foundation

The Tula Trust

William Howarth Charitable Trust



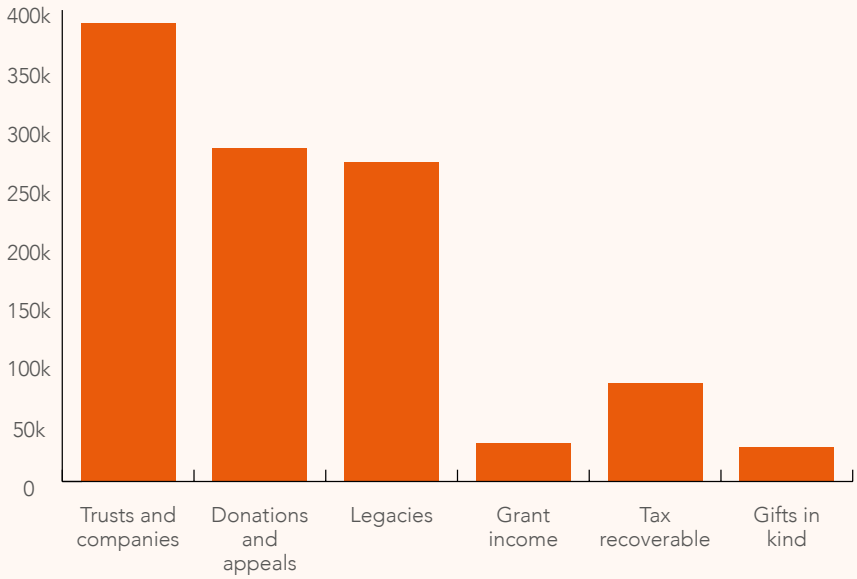




Our Finances

This year saw a significant improvement in income against the previous year to £1.7m, thanks to increased trust and legacy income together with the income from our 'Breakthrough ME' fundraising dinner. Meanwhile we have maintained our expenditure level in line with last year that means our overall net result is a small deficit. Our current reserve position remains ahead of the Trustee target at £1.3m while our cash is also showing a healthy position at £1m. 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.

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 of our total gross expenditure is on staff salaries.



This year, we spent:

£855k
on our information, advocacy, peer support and healthcare services for adults, young people and families with ME.

£295k
on our campaigning and influencing work.

£194k
on our investment in collaborative biomedical research.

£445k
on fundraising.



During 2023 – 2024 we raised £3.62 for every £1 invested in fundraising.

Summary Statement of financial activities

	2024 (£'000)	2023 (£'000)
Incoming Resources	1,735	1,123
Resources Expended	1,789	1,795
Net gains/(losses) on Investments	-	(3)
Net Movement in Funds	**(54)**	**(675)**
Fund balance 31 March 2024	**1,326**	**1,380**

Summary Balance Sheet

	2024 (£'000)	2023 (£'000)
Fixed Assets	55	64
Net Current Assets	1,271	1,316
Total Assests less Current Liabilities	**1,326**	**1,380**
General Funds	490	538
Designated Funds	413	668
Unrestricted Funds	903	1,206
Restricted Funds	423	174
Accumulated Funds	**1,326**	**1,380**

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 3-14.

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, 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 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 2024. 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 organisation and alliances, including Forward ME, 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 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. grantgiving 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 were 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 ME, 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 2023-2024.

Financial review

Statement of financial activities

Our annual Big Give Christmas Challenge fundraising campaign was successful for the seventh year running, raising £120k in income to support our Services, Healthcare 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 £491k (down £48k against last year). In addition, the charity has designated reserves of £413k.

Restricted reserves were £423k (down £249k against last year) which will continue to be expended over the course of the next year on service delivery and the research fellowship. 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 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.

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

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. In 2021 the charity invested £50k in the M&G Charibond which, as of March 2024, had a net value of £45k.

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. The charity ended the financial year with 7.8 months of unrestricted reserves (£904k) This is based on an average monthly unrestricted expenditure rate of £116k.

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.

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.

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 2023 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 and affected by ME has never been stronger. Moving into 2024-2025, we've laid out our priorities to amplify the impact we can create together.

With increasing numbers of people with ME or ME-like symptoms following a Covid-19 infection, and the impact of long Covid becoming clearer, our dedication to research remains an essential commitment. In the coming year, we will continue to drive and fund high-quality research into the condition, collaborating with researchers and other organisations to uncover effective diagnostic tests and treatments to drastically improve the lives of people with ME.

We will continue to work closely with Government and other stakeholders to generate awareness and ensure the National Delivery Plan on ME/CFS is not only published in full, but implemented effectively, in order to have the greatest benefit and positive change for people affected by the condition.

We will remain committed to expanding our Support and Healthcare Services, with a focus on improving access to ensure that every person affected by ME can access the vital support they need, when they need it most. The people we support will remain firmly at the centre of work, recognising the importance of providing person-centric care and support, whilst ensuring a level of professionalism and trust in all that we do.

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.

As we move into the final two years of our organisational strategy, we know there is still much to do, but we remain undeterred and committed. Working collaboratively, with your continued support and determination, I am confident that we will continue to improve the lives of the children, young people, and adults affected by ME.



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 7 October 2024.

Report of the Independent Auditors to the Members 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 2024 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 2024 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 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 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 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 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; 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 exemption 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 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.

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, 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 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 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 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.

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 Moore Chartered Accountants and Statutory Auditor

30 Gay Street
Bath
BA1 2PA

Date: 11 October 2024

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2024

	Notes	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2024 (£'000)	Total 2023 (£'000)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	856	343	1,199	813
Other trading activities	3	273	63	336	162
Investment income	4	24	-	24	8
Incoming resources from charitable activities	3	78	98	176	140
Total incoming resources		**1,231**	**504**	**1,735**	**1,123**
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	445	-	445	280
Fundraising trading: costs of goods sold and other costs		-	-	-	2
Charitable activities	5	1,089	255	1,344	1,513
Total resources expended		**1,534**	**255**	**1,789**	**1,795**
Net gains/(losses) on Investments		**-**	**-**	**-**	**(3)**
Net movement in funds	12	(303)	249	(54)	(675)
Reconciliation of funds					
Fund balance at 1 April 2023		1,206	174	1,380	2,055
Fund balances at 1 April 2024		**903**	**423**	**1,326**	

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 2024 (company registered number 2906840)

	Notes	2024 (£'000)	2023 (£'000)
Fixed assets			
Tangible assets	9	10	20
Investments	10	45	44
Total fixed assets		**55**	**64**
Net current assets			
Debtors	11	299	148
Cash at bank and in hand		1,066	1,277
Total current assets		1,365	1,425
Creditors: Amounts falling due within one year	12	(94)	(109)
Net current assets		1,271	1,316
Total assets less current liabilities		**1,326**	**1,380**
Capital and reserves			
General funds		490	538
Designated funds	13	413	668
Unrestricted funds		**903**	**1,206**
Restricted funds	**14**	**423**	**174**
Accumulated funds		**1,326**	**1,380**

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 7 October 2024

Action for M.E. cash flow statement for the year ended 31 March 2024

		2024 (£'000)	2023 (£'000)
Net cash flow from operating activities	See note a below	(235)	233
Net cash flow from investing activities	See note b below	24	2
Net increase in cash and cash equivalents		(211)	235
Cash and cash equivalents at beginning of period		1,277	1,043
Cash and cash equivalents at end of period		1,066	1,277

Cash flows from operating activities

	2024 (£'000)	2023 (£'000)
Net movement in funds	(54)	(675)
Depreciation	9	15
(Gains)/losses on investments	-	3
Financial income	**(24)**	**(9)**
	(69)	(665)
(Increase)/decrease in debtors	(151)	908
a (Decrease)/increase in creditors	(15)	(10)
b Net cash from operating activities	(235)	233

Cash flows from investing activities

	2024 (£'000)	2023 (£'000)
Purchase of tangible fixed assets	-	(7)
Interest received	24	9
Investment in financial assets	-	-
Net cash from investing activities	24	2

	At 01.04.2023 (£'000)	Cash Flow (£'000)	At 31.03.24 (£'000)
Cash at Bank	**1,277**	**(211)**	**1,066**

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 p39. 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 received 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 £64,192 (£65,334 in 2023).

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 2024 (£'000)	Total 2023 (£'000)
Donations and legacies				
Trusts and companies	114	275	**389**	189
Donations and appeals	353	30	**383**	444
Legacies	271	-	**271**	66
Grant income	-	33	**33**	21
Tax recoverable	79	5	**84**	71
Gifts in kind	39	-	**39**	22
	856	**343**	**1,199**	**813**
Other trading activities				
Events	220	-	**220**	-
Lotteries and raffles	8	-	**8**	9
Christmas cards	2	-	**2**	4
Supplement commission	3	-	**3**	2
Merchandise	-	-	**-**	2
Other	40	63	**103**	145
	273	63	**336**	162
Incoming resources from charitable activities				
Subscriptions	77	-	**77**	80
Healthcare services	-	99	**99**	59
	78	**99**	**176**	**139**

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 £38,973 based on number of hours worked.

Details of 2023 income	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2023 (£'000)
Donations and legacies			
Trusts and companies	130	**59**	**189**
Donations and appeals	405	**39**	**444**
Other legacies	66	**-**	**66**
Grant Income	-	**21**	**22**
Tax recoverable	63	**8**	**71**
Gifts in kind	22	**-**	**21**
	686	**127**	**813**
Other trading activities			
Lotteries and raffles	9	**-**	**9**
Christmas cards	4	**-**	**4**
Supplement commission	2	**-**	**2**
Merchandise	-	**2**	**2**
Other	70	**75**	**145**
	85	**77**	**162**
Incoming resources from charitable activities			
Supporting Membership	80	**-**	**80**
Healthcare services	-	**59**	**59**
	80	**59**	**139**

4 Investment income

		2024 (£'000)	2023 (£'000)
Interest from cash investments in the UK		**24**	9

5 Resources expended

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2024 (£'000)	Total 2023 (£'000)
Costs of generating voluntary income				
Staff costs	80	-	**80**	44
Direct fundraising costs	98	-	**98**	20
Support costs – see below	267	-	**267**	216
	445	**-**	**445**	**280**

	Unrestricted funds (£'000)	Restricted funds (£'000)	Total 2024 (£'000)	Total 2023 (£'000)
Charitable activities				
Information and support services	688	167	**855**	880
Campaigning and influencing work	289	6	**295**	337
Collaborative biomedical research	112	82	**194**	296
	1,089	**255**	**1,343**	**1,513**

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

	Activities directly	Support costs undertaken as below	Total (£'000)
Charitable activities			
Information and support services	333	**355**	688
Campaigning and influencing work	174	**115**	289
Collaborative biomedical research	48	**64**	112
	555	**534**	1,089

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	56	25	226	29	355
Campaigning and influencing work	6	18	8	73	10	115
Research	3	10	5	41	5	64
	28	**84**	**38**	**340**	**44**	**534**
Fundraising	14	42	19	170	**22**	267
	42	**126**	**57**	**510**	**66**	**801**

Office costs include £155,892 (£21,747 in 2023) for professional services in kind.

	2024 (£'000)	2023 (£'000)
Governance costs		
Administrative salaries – based on time spent	**30**	31
Indemnity insurance for Trustees	**1**	2
Trustees' expenses	**-**	1
Auditors' fees	**10**	7
Design and printing	**1**	1
	42	42

	2024 (£'000)	2023 (£'000)
Grant activities		
The University of Edinburgh – PhD. in biomedical research	-	9
The University of Oxford- PhD. In biomedical research	-	15
Kings College London – PhD. in biomedical research	-	15
	-	39

Details of 2023 expenditure

	Unrestricted funds (£'000)	Restricted funds (£'000)	**2023 (£'000)**
Costs of generating voluntary income			
Staff costs	44	-	**44**
Direct fundraising costs	20	-	**20**
Support costs – see below	216	-	**216**
	280	**-**	**280**
Charitable activities			
Information and support services	693	187	**880**
Campaigning and influencing work	333	4	**337**
Collaborative biomedical research	145	151	**296**
	1,171	**342**	**1,513**

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

	Activities directly	**Support costs undertaken**	as below Total (£'000)
Activity			
Information and support services	304	**389**	693
Campaigning and influencing work	204	**129**	333
Collaborative biomedical research	33	**112**	145
	541	**630**	**1,171**

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	55	20	271	24	389
Campaigning and influencing work	6	18	6	90	8	129
Research	6	16	5	78	7	112
	31	**90**	**32**	**439**	**39**	**630**
Fundraising	11	31	11	150	13	216
	42	**120**	**43**	**589**	**52**	**846**

6 Net movement in funds

	2024 (£'000)	2023 (£'000)
This is stated after charging:		
This is stated after charging:		
Operating lease	**39**	37
Depreciation of owned fixed assets	**9**	15
Auditor remuneration	**10**	7
Trustees' expenses	**-**	1
Pension costs	**69**	68

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 2024 was £1,289 (£2,068 in 2023).

7 Staff costs and emoluments

	2024 (£'000)	2023 (£'000)
Gross salaries	**872**	959
Employer's National Insurance	**77**	85
Employer's Pension contributions	**30**	32
	979	1,076

	2024	2023
Average number of employees		
Engaged on charitable activities	**24**	25
Engaged in fundraising activities	**6**	6
Engaged on management and administration	**5**	9
	35	40

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	**2**	1
£100,000 - £110,000	**1**	1
Total	**3**	2

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 £107,248 (£102,249 in 2023).

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

	2024 (£'000)	2023 (£'000)
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.	**-**	1
Amounts of expenses incurred by Trustees that were donated back to the Charity.	**-**	-

There were no related party transactions up to 31 March 2024.

9 Tangible fixed assets

	Office equipment (£'000)
Cost	
At 1 April 2023	87
Additions for year	-
Disposals in year	35
At 31 March 2024	**51**
Depreciation	
At 1 April 2023	67
Charge for year	9
Disposals in year	35
At 31 March 2024	**41**
Net Book Value	
At 31 March 2023	19
At 31 March 2024	**10**

10 Investments

Market value	
At 1 April 2023	44
Revaluations	-
At 31 March 2024	**45**
Net book value	
At 31 March 2023	44
At 31 March 2024	**45**

There were no investment assets outside of the UK

11 Debtors

	2024 (£'000)	2023 (£'000)
Trade debtors	**28**	68
Prepaid expenses	**42**	31
Due from HMRC	**4**	-
Accrued income	**225**	49
	299	148

12 Creditors: amounts falling due within one year

	2024 (£'000)	2023 (£'000)
Trade creditors	**45**	44
Accrued expenses	**26**	37
Unpaid pension contributions	**6**	5
Other taxation and social security costs	**17**	23
	94	109

13 Funds

	General funds (£'000)	**Designated funds (£'000)**	**Total (£'000)**
Statement of unrestricted funds			
Balance at 1 April 2023	538	668	**1,206**
Transfer between funds	200	(200)	**-**
Surplus for year	(248)	(55)	**(303)**
Balance at 31 March 2024	**490**	**413**	**903**

	Tangible fixed assets (£'000)	**Cash**	**Other net current assets (£'000)**	**Total (£'000)**
Analysis of net assets between funds – current year				
Unrestricted funds:				
General funds	55	451	(16)	**490**
Designated funds	-	413	-	**413**
	55	864	(16)	**903**
Restricted funds	-	202	221	**423**
	55	**1,066**	**205**	**1,326**

	Tangible fixed assets (£'000)	**Cash**	**Other net current liabilities (£'000)**	**Total (£'000)**
Analysis of net assets between funds – prior year				
Unrestricted funds:				
General funds	64	459	15	**538**
Designated funds	-	668	-	**668**
	64	1,127	15	**1,206**
Restricted funds	-	150	24	**174**
	64	**1,277**	**39**	**1,380**

14 Restricted Funds

	Opening balances (£'000)	Incoming rersources (£'000)	Outgoing resources (£'000)	Closing balances (£'000)
Statement of unrestricted funds				
Research	128	70	25	**173**
DecodeME	-	57	57	**-**
Services	23	112	131	**4**
Learn about M.E.	11	33	22	**22**
M.E. Advocacy	8	-	8	**-**
Breaking Isolation	4	-	4	**-**
Children and Young Persons Counselling Service	-	226	2	**224**
Campaigning and Influencing	-	6	6	**-**
	174	504	255	**423**

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.

Services – funding to increase our reach to people of all ages affected be ME, including family members, offering information, resources, signposting, support and understanding, and healthcare

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

ME 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 ME in Scotland.

Children and Young Persons Counselling Service – funding from the National Lottery Community Fund to provide free counselling to children and young people, aged 13 to 18, with either diagnosed or suspected ME.

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 £5,808 (£5,470 in 2023) 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 2024 (£'000)	Total Leases 2023 (£'000)
Operating lease payments falling due:		
within one year	40	36
within two to five years	110	144
over five years	–	–
	150	**180**

17 Contingent assets

The chatiry has been advised of a legacy of £40,000 which at year end is pending an application for a grant of probate.

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 £268,163 of which £104,059 is to be spent in the year to 31 March 2025.

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

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

Vice President
Martin Arber

Patrons
Lord Bragg
Julie Christie
Lord Puttnam CBE
Alan Cook CBE
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Honorary Patron
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Julianne Devine
Sue Hardy
Rollo Hope
David Leigh
Jane Stacey
Matt Symonds
Nirmala Santiapillai
Eleanor Bulmer (joined September 2023)
Jeff Banks (joined February 2024)

Chief Executive
Sonya Chowdhury

Principal Medical Adviser
Prof David Strain

action for m·e

Want to shape the future with us?

Learn, donate, volunteer, share your view or get support now at

www.actionforme.org.uk

Email: questions@actionforme.org.uk

Tel: 0117 927 9551

@actionforme

@actionform.e

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

Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452
Company limited by guarantee, registered in England no. 2906840
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ACTION FOR ME

England & Wales - Charity number 1036419

Accounts

Action for M.E. Trustees' report

2022 – 2023









action for m·e



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.

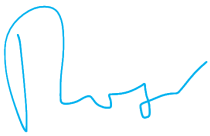
This includes another successful Big Give Christmas Challenge fundraising campaign, raising £155,610.

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

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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

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

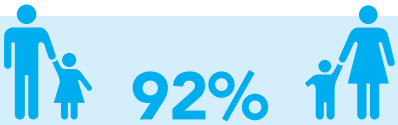
across all major streaming sites

A total of

74.8m people

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





92%

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

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



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 effecitvely 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.

BBC Children in Need

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 wating 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 imaged, 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."

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.

"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."



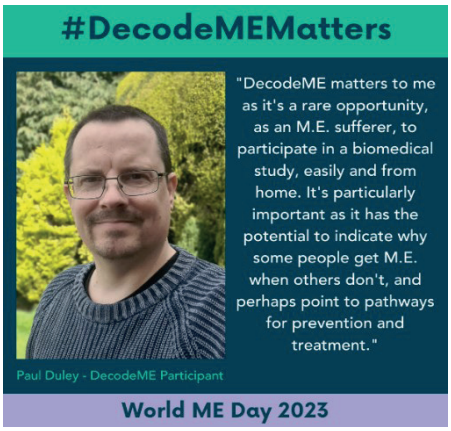
Increased funding for high-quality research by more researchers leads to effective treatments for M.E.

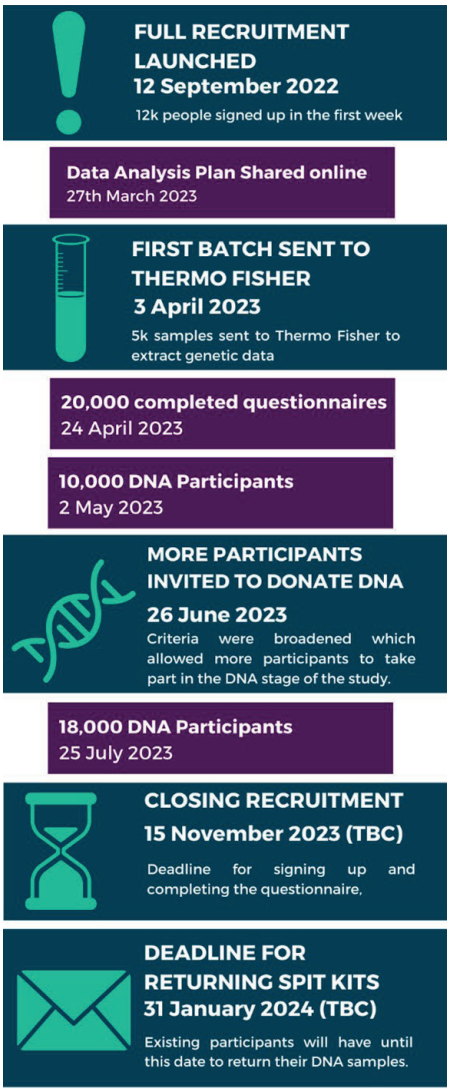
DecodeME is the world's largest study investigating the causes of M.E./CFS, led in partnership by Action for M.E. and the University of Edinburgh (UofE), with a steering group of people with lived experience.

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 provided 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.decodeme.org.uk**





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 needs 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.

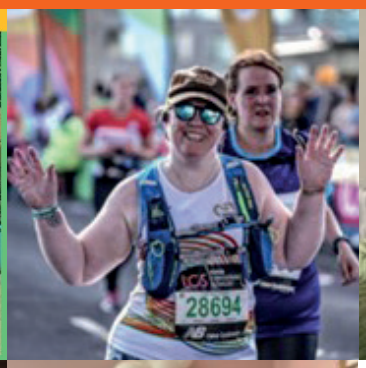
Our volunteers

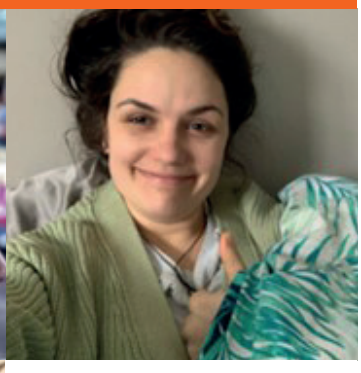
We also want to thank all our dedicated volunteers who help to proof-read our *InterAction* magazine, moderate our forums, write Birthday and Christmas cards, support the running of our Listen to M.E. service, and much more.

Partnering organisations

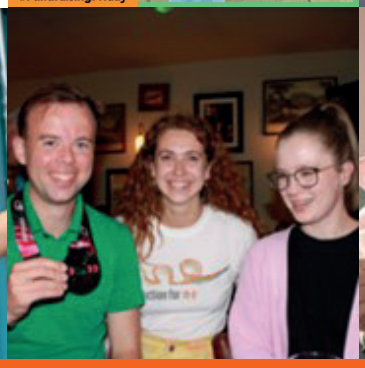
Finally, a thank you to all the organisations we work closely with to support people with M.E. now, whilst securing change for the future.

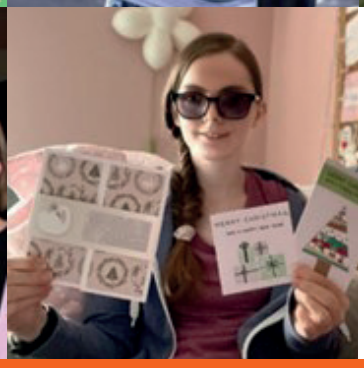












Our finances

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**.

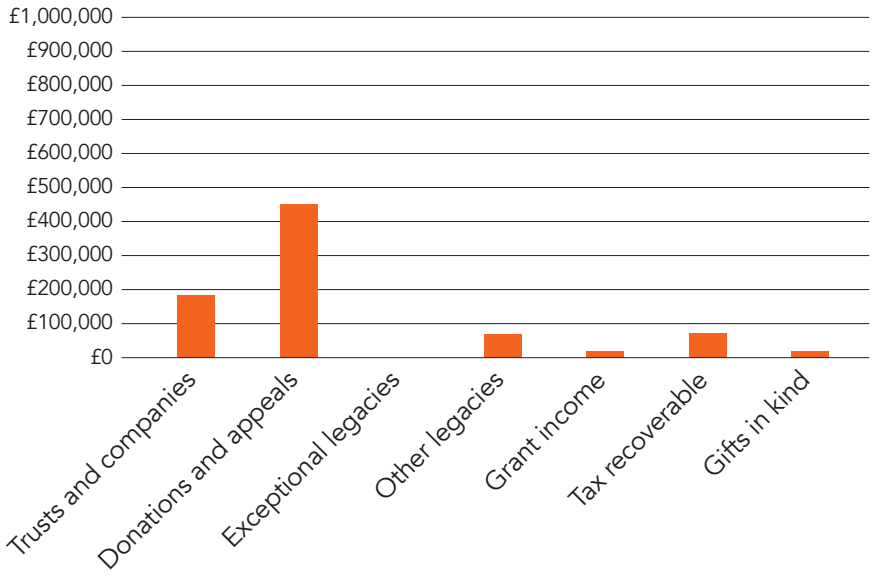
The Trustees and management agreed on an investment strategy in both staff and charitable activities for the current financial year and hence overall expenditure was £1.8million, an increase of 35% from the previous year.

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 our 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.

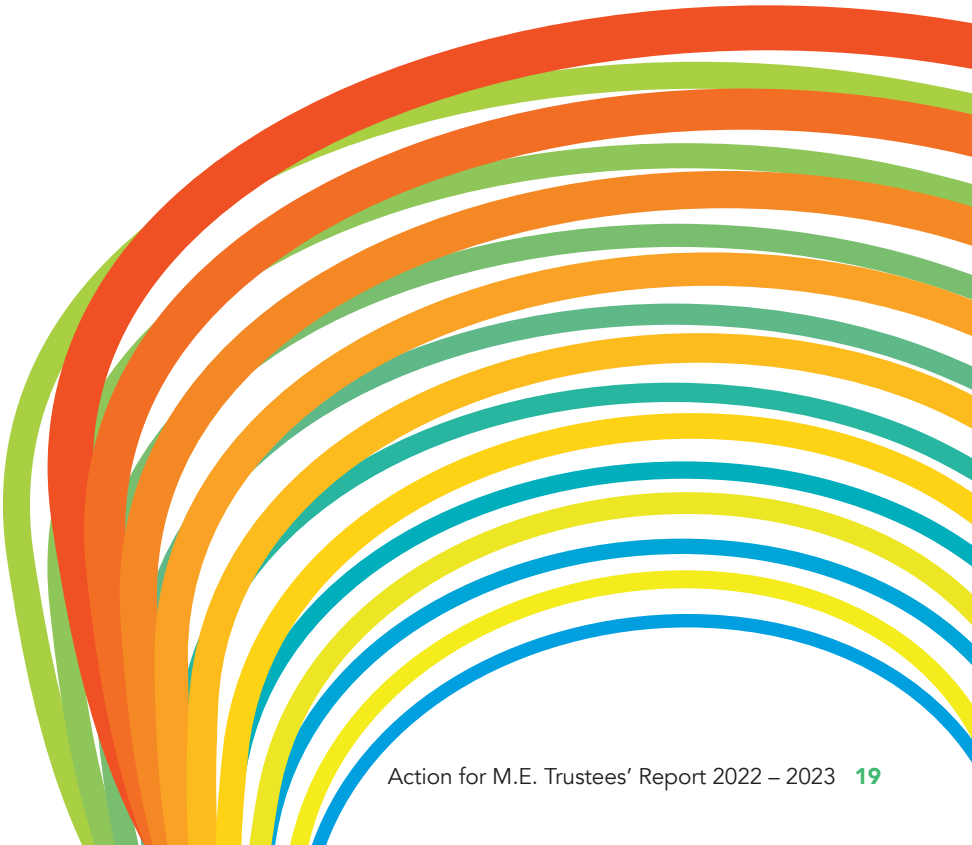
Our fundraising policy stresses the critical importance that no individual should use their position in Action for M.E. for personal gain, or to benefit others at the expense of the charity, our mission, or our reputation. It sets out that individuals must not act in any way that could be reasonably 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 acrruals 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 received 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

	2023 (£'000)	2022 (£'000)
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.	1	0.5
Amounts of expenses incurred by Trustees that were donated back to the Charity.	–	0.3

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

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 be 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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Vice President

Martin Arber

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(joined September 2022)

Chief Executive

Sonya Chowdhury

Principal Medical Adviser

Dr David Strain



WANT TO SHAPE THE FUTURE WITH US?

Learn, donate, volunteer, share your view or get support now at

www.actionforme.org.uk

Email: questions@actionforme.org.uk

Tel: 0117 927 9551

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@actionform.e

42 Temple Street, Keynsham BS31 1EH
Crisis, Advocacy and Support Service: 0117 927 9551
Email: questions@actionforme.org.uk
www.actionforme.org.uk

Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452
Company limited by guarantee, registered in England no. 2906840
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ACTION FOR ME

England & Wales - Charity number 1036419

Accounts

Action for M.E. Trustees' report

2021 – 2022



action for m·e

Led by people with M.E., sharing support now...

As the population emerged into finding their new normal following Covid-19 lockdowns across the UK, many people with M.E. felt – and still feel – an overwhelming sense of isolation.

People with M.E. reached out to us seeking information, support and hope from someone who understands, with more than 1,695 enquiries over the year for our Information and Support, Family Support and Advocacy services. When surveyed, all clients said they were satisfied or very satisfied with the support they received.

One person told us: "I was hugely impressed and grateful to [Action for M.E. Information and Support Officer] Anna for her support, understanding, care and consideration. You helped me to feel I had a voice and a way forward."

These frontline services continue to be a lifeline for people with M.E. but there is still much to be done to end the ignorance, injustice and neglect they face every day.

The life-changing symptoms experienced by people with M.E. are being mirrored by more than half of those with Long Covid – an estimated 1.3 million people in the UK. In response to this public health crisis and gaps in existing service provision for people with M.E., our merger this year with UK charity The ME Trust has allowed us to combine the power of our organisations and strengthen the services we offer.

The launch of our new Healthcare Services in February 2022 brought a highly skilled and knowledgeable clinical team to Action for M.E. We are now looking to expand our team of Doctors, Physiotherapists, Counsellors, and Multi-Faith Chaplains to meet increasing need. A few months prior to this, we welcomed the long-overdue publication of the updated National Institute of Health and Care Excellence guideline for the diagnosis and management of M.E. Arrived at in consultation with the M.E. community, it marked another step along the road to recognition of those with lived experience of M.E. as experts and leaders of change.

The M.E./CFS Priority Setting Partnership has provided another powerful opportunity for the voices and experiences of children and adults with M.E. to be heard. Over the year, thousands took part in surveys and workshops facilitated by Action for M.E., working alongside the James Lind Alliance, to share the research questions they want to see prioritised. More than 5,300 ideas were submitted, resulting in a Top 10+ list published in May 2022.

People with M.E. are also at the heart of DecodeME, the world's largest genetic study we are co-leading. After some initial setbacks – inevitable in a study of this size, and during a pandemic – DecodeME's test phase launched in January 2022, with early participants sharing feedback to help the team refine their approach.
In all our activities, alongside people with M.E., we work with a range of health, social care, education, and research professionals, who offer their their personal, professional and clinical experience to help shape our work and our priorities. We are grateful to them – and to you, our supporters, because we cannot achieve our big ambitions alone.

Our new five-year strategy, launched just after year end in May, sets out four key ambitions. One of these calls on the UK Government to establish and lead a national strategy for M.E. They have now done just that, choosing the first World M.E. Day to announce they would publish plans later this year for a cross-Government delivery plan on M.E.

The statement made by then Secretary of State for Health and Social Care, Sajid Javid, read by Health Minister Lord Kamall, said: "At the heart of the delivery plan will be two core principles. Firstly, that we do not know enough about M.E./CFS, which must change if we are to improve experiences and outcomes. Secondly, we must trust and listen to those with lived experience of M.E./CFS."

Action for M.E. is now supporting the work that has started to take this plan forward, working alongside people with M.E., and Government and frontline professionals across health, education, welfare benefits, employment and social care.

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.

...and creating change for the future

As we adapt to live with Covid-19, things have not become easier for disabled people, and those living with long-term conditions like M.E. That means our services, resources and support, and our ambitious plans for the future, are more essential than ever.

We have seen the increased demand for our services, prompted by national and local lockdowns, continue. Our dedicated services teams – now crucially including healthcare alongside information, support and advocacy – are spending longer with the children, young people and adults we support, as the complexities of the challenges they face increases. The information, resources and reassurance they get enables them to make informed decisions about their care.

We know that this demand will only increase, and we must grow to meet the need. Thanks to unwavering support from you – our donors, funders, fundraisers, supporters, volunteers and the M.E. community – we have seen our recorded total income for the year increase by 110% from the previous year to £2.5 million.

This includes an exceptional legacy of £1.3 million and, for the fifth year running, a target-busting Big Give Christmas Challenge fundraising campaign. This surpassed expectations to raise £133,804 to support our information, support and advocacy services, medical education to increase understanding of M.E. among health professionals, and our collaborative research work.

As a result of our increased funding, we have been able to do more, investing more in collaborative biomedical research, reinforcing our services and adding healthcare, and bringing more capacity and expertise to the team.

This has helped secure the foundations on which we are now building towards the four ambitions in our 2022 – 2027 strategy, focused on people with M.E. being able to:

- access the information, support and advocacy they need
- improve their health via our holistic Healthcare Services, and effective NHS implementation of the updated 2021 National Institute for Health and Care Excellence (NICE) guideline for M.E.
- have hope for the future through increased funding for high-quality research, leading to effective treatments for M.E.
- have confidence that the UK Government's Delivery Plan for M.E., announced in May 2022, will lead to genuine change.

You can read more about how we are already working towards these ambitions on p 12-13.

There have been a number of milestone events for people with M.E. during the year. I am proud of the contribution that people working with Action for M.E. have made to those achievements, and would like to recognise and thank them for their efforts.

In fact, to everyone who has made this possible, thank you. We can only do what we do with your support.





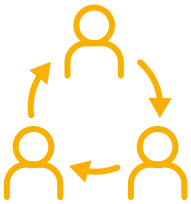
Roger Siddle
Chair of Board of Trustees
Action for M.E.

"As a result of our increased funding, we have been able to do more, investing more in collaborative biomedical research, reinforcing our services and adding healthcare, and bringing more capacity and expertise to the team."

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Our year in numbers



More than

240

people connected with our independent advocacy service

100%

of adult forum users who replied to a survey about their experience agreed that, because of using the forum, they feel less isolated

We supported

130

members in our Young Persons' Forum



80%

of parents felt in a stronger position to support their child after contacting our Family Support service



Episodes of our Learn about M.E. podcast have been downloaded

1,840

times across all major podcast streaming sites

77%

of attendees of the Breaking Isolation workshops funded by BBC Children in Need said they have increased self-esteem as a result

"I had a great time making it and taking part in the workshops. I just wanted to let you all know how much I appreciated the feeling of being listened to. It's something I'm sure a lot of other people my age with M.E. don't get too often."

So far around

31,000

people in the UK have registered interest to take part in DecodeME, the world's biggest M.E. DNA project



"My counselling sessions have been a lifeline. My counsellor is always caring, understanding and compassionate and I always feel listened too and understood. My physio sessions have also been extremely helpful, and she always provides practical advice on how to manage or improve my symptoms and condition."

"I sent the @actionforme template letter requesting the vaccine to my GP and I'm getting my COVID vaccine on Saturday."

More than

1,500

people with lived experience of M.E. shared their views with us about the draft NICE guideline.

86%

of Information and Support clients reported increased understanding of their rights and options



Our booklets, guides and factsheets have been downloaded

33

times every working day

A total of

31.3 million

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



Children and adults with M.E. feel informed, supported and less isolated.



People with M.E. got the facts, resources and reassurance from our Information and Support team service

1,560 times.

Many people with M.E. who reached out to our Information and Support, Advocacy and Family Support services felt that we were their only avenue for accessing support.

"The support you offer is incredible. I wouldn't have been able to challenge my social services care needs report without Sally's help."

COMMUNITY FUND

Work like this would not be possible if it weren't for funders like the National Lottery. Funding raised by National Lottery players has helped us provide information and support to people with M.E. who often have nowhere else to turn.

As a result of their contact with our service:

- **86%** had increased understanding of their rights and options
- **84%** felt less isolated
- **84%** had increased knowledge of other services they can access
- **76%** had increased confidence communicating with professionals.

More than 240 people connected with our independent Advocacy service, through online workshops, or one-to-one casework support which we delivered to 65 adults and 10 children and young people with M.E.

We work at our clients' pace, which for some means only short contact by text to minimise impact on their symptoms. One of our young clients said:

"Many people wouldn't think to ask if someone typing on a keyboard while speaking on the phone would be too loud, or trigger symptoms. But Jacqueline asked if I had noise sensitivity. I've never felt more validated and understood when talking about my health than when using Action for M.E.'s Advocacy service."

Foundation SCOTTISHPOWER

We would like to thank The ScottishPower Foundation for helping to fund our Advocacy service, including recruiting volunteers and providing online workshops for people with M.E., helping them to get their voices heard, explore barriers to accessing services and self-advocacy.

Attending workshops led by our experienced advocates has empowered people with M.E. to share experiences and develop self-advocacy skills. Topics covered include barriers to accessing services and support and social care in England.

One attendee said: "It was well-prepared, presented in a professional way and there were lots of useful phrases and explanations of the Care Act including legal terms, along with practical examples of care needs with regard to M.E./CFS."

On 1 February 2022, we launched our new Healthcare Services following a successful merger with The ME Trust.

Helen Winning, our Director of Healthcare Services, said: "This means that we can expand the healthcare services previously offered by the ME Trust and reach more people with M.E. and their families. We continue to adopt a whole person approach, helping them to manage their symptoms and improve their quality of life."



In February and March alone, our clinical team supported more than 170 people with M.E. We are now looking at how we can scale up the existing holistic support from our clinical team of Doctors, Physiotherapists, Counsellors, and Chaplains.

"My counselling sessions have been a lifeline. My counsellor is always caring, understanding and compassionate and I always feel listened too and understood. My physio sessions have also been extremely helpful, and she always provides practical advice on how to manage or improve my symptoms and condition."

With more people diagnosed with M.E. after the Covid -19 pandemic, we need your support more than ever to reach people with M.E. You can support our vital services by becoming a member or donating to our work at www.actionforme.org.uk/donate-online



Our Family Support Officer supported parents and guardians of children and young people with M.E. more than 60 times, with two thirds facing challenges securing the education their child is entitled to. As a result:

- **100%** felt more confident communicating with professionals.
- **80%** felt in a stronger position to support their child.

J is 11 years old and has M.E. His mum H got in touch because J's school didn't fully understand M.E. and how it affected him. This led pressure about his attendance, despite J not having any unauthorised absences, which was incredibly stressful for the family.

With the help of our Family Support Officer, J and H felt better able to communicate effectively with the school. As a result, J was able to go back to school three days a week, managing his symptoms alongside balancing his schoolwork. H said:

"It's been hard when the advice of professionals and the school are not in line with what J needs, so it's really encouraging to have your point of view. Thank you again for your support and reassurance about how we are managing things."

More than 40 children and young people with M.E., aged between eight and 18, took part in our Breaking Isolation workshops, funded by BBC Children in Need, some of them meeting others with M.E. for the first time.

Four young people who took part in the June 2021 workshop shared their creative work in Cheers, our monthly e-magazine written by and for young people with M.E. One told us:

"I had a great time making it and taking part in the workshops. I just wanted to let you all know how much I appreciated the feeling of being listened to. It's something I'm sure a lot of other people my age with M.E. don't get too often."

Some workshop participants have gone on to join our online Young People's Forum; we supported 130 forum users over the year.

- **77%** of attendees said they have increased self-esteem as a result.
- **100%** of forum users who replied to a survey about their experience agreed that, because of using the forum, they feel less isolated.

Supported by BBC Children in Need

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Led by expert patients and experienced professionals, we regularly review our website information and downloadable/ printed resources to ensure that people affected by M.E. are able to develop a better understanding of how to manage living with symptoms, make informed decisions, and understand how to access appropriate care and support



Our booklets, guides and factsheets were downloaded 33 times every working day

(8,322 times over the year) while our website pages were viewed 2.5 times every single minute.

"I sent the @actionforme template letter requesting the vaccine to my GP and I'm getting my COVID vaccine on Saturday."

People making decisions that affect the lives of people with M.E. are better informed

Through amplifying the voices of the M.E. community and engaging with politicians and healthcare professionals, we have inspired action at all levels.

Since 2020 we have been working in partnership with #MEAction Scotland, The M.E. Association and The 25% ME Support group to promote a Continuing Professional Development training module on M.E./CFS aimed at healthcare professionals. The project is funded by the Scottish Government Clinical Priorities Unit.

The module has so far been accessed by **600 health professionals in Scotland**.

- **77%** reported increased confidence in treatment and management of M.E.
- **75%** reported an increase in confidence at diagnosis stage.

The module has been supported by our Learn about M.E. podcast series, covering topics including M.E. and Long Covid and the new NICE guideline on M.E., published in October.

"This module was concise, informative, and provided evidence-based explanations. It has greatly helped my understanding of diagnosis and management of M.E./CFS."
Dr Shaun Peter Qureshi

Those who took the module expressed an interest in learning more about other key issues affecting people with M.E. Using this feedback, we hosted a webinar dedicated to **expanding social care professionals' knowledge**.

- **88%** of participants said they felt more confident now that they understood what care and management strategies people with M.E./CFS and Long Covid need.

Episodes have been downloaded more than 1,840 times across all major podcast streaming services. By increasing understanding among professionals, our aim is that people with M.E. experience lower levels of ignorance, injustice, and neglect.



A total of 31.3 million people had the chance to see our interviews, letters and stories in newspapers and magazines, including Daily Mail, BBC News, Guardian, The Times, Huffington Post, The Sunday Telegraph and The Sunday Express. This saved us the equivalent of £1,019,110 in advertising costs to gain similar coverage.

In November, we welcomed actor Jennie Jacques as an Action for M.E. Ambassador, after we reached out to see if she would be open to doing an interview with The Times (pictured). Jennie said: "I'm excited to join forces with Action for M.E. Moving forward, I endeavour to continue raising awareness for virus-initiated illness, utilising my platform."

We have supported people with M.E. to have their voices heard by using their insight and experiences to respond to a range of Government consultations including **two House of Commons Select Committee enquiries**.

Parliamentarians have joined the reformed All-Parliamentary-Party Group on M.E. (APPG), chaired by Carol Monaghan MP, to gain a better understanding of the challenges facing their constituents with M.E. We jointly provide the APPG Secretariat alongside the ME Association.

In November, Sonya took part in a meeting held by the then Secretary of State for Health and Social Care, Rt Hon Sajid Javid MP. This gave people with lived experiences and researchers an opportunity to discuss challenges with change makers, with Mr Javid tweeting about the need for **more research, recognition and collaboration**.

Since this meeting, the Department of Health and Social Care have committed to taking forward a **Delivery Plan for M.E./CFS**, the first time that Government has made such an explicit and dedicated statement on M.E.





More than 1,500 people with lived experience of M.E. shared their views with us about the draft NICE guideline, resulting in a new guideline, published October 2021, setting out a significant change in approach, including:

- recommending energy management techniques to avoid post-exertional malaise, a hallmark symptom of M.E.
- clearly stating that any therapy based on physical activity or exercise should not be offered as a cure for M.E./CFS.

Previously, people with M.E. were offered graded exercise therapy (GET), based on a hypothesis that they were deconditioned. NICE found the evidence for this to be of poor quality, and many people with M.E. reported that GET caused serious harm.

Our medical advisor, Dr David Strain, said: ***"The guideline should drive better acceptance of M.E. as a serious medical condition and encourage doctors to personalise care based on individual needs. It is a real opportunity for doctors to transform the care patients receive."***

As part of UK M.E. charity collective Forward-ME, we have been contacting NHS clinics to highlight the changes that are now needed to ensure effective implementation of the guideline, led by people with M.E. sharing their experiences at centres across the UK.

In June, people with M.E. began joining our new **Act4ME network**, launched to help drive change, led by the M.E. community. With the aim of placing pressure on decision makers to prioritise M.E., members of the network commit to one action a month, including:

- contacting Jonathan Ashworth MP to request he meet with Sonya Chowdhury to discuss the importance of greater support and awareness for those with M.E./CFS
- asking local decision makers to add their support to the #MEAction petition
- highlighting key research like DecodeME or the Priority Setting Partnership
- sharing the essential NICE guideline update with GPs
- encouraging MPs to engage and participate in parliamentary debates effecting the lives of people with M.E.

In addition, people with M.E. have used our template letters to:

- highlight updates to the NICE guideline with their allied health professional
- encourage their MP to attend All Parliamentary Party Group meetings
- promote online learning and support for diagnosing and managing M.E. to their GP.

People with M.E. are at the heart of plans to grow more research

Breakthrough-ME
Driving Breakthrough Research to end ME

Just before the end of the year, we launched our Breakthrough-ME strategy, our plan to rapidly grow research and funding.

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

Breakthrough-ME builds on significant progress we have made by working collaboratively, like co-leading the world's largest M.E. genetic study, DecodeME.



Partnering with Prof Chris Ponting (pictured), we pledged to host a genetics research symposium to stimulate new studies (taking place September 2022) and establish the first M.E. Genetics Centre of Excellence. Prof Ponting says:

"DecodeME cannot be the last M.E./CFS research project funded by taxpayers. Currently, low-level funding is yielding low-level evidence that fails to reach the high level of evidence required for competitive funding. Funders should act now and break this vicious cycle."

DecodeME timeline

Study expanded for 5,000 post-Covid
August 2021

DNA collection tested by team
December 2021

Testing phase commenced
Jan 2022

Questionnaire redesign began
Feb/March 2022

Planned launch date
September 2022

Decode ME
The ME/CFS Study

So far around 30,000 people in the UK have registered interest to take part in DecodeME, the world's biggest M.E. DNA project, thanks to the work of its Patient and Public Involvement (PPI) Steering Group, made up of people representing groups or networks from the M.E. community. They work with the Management Group to put PPI at the heart of the research project.

DecodeME isn't just a study for people with M.E./CFS. It's a study by people with M.E./CFS.

The scope of DecodeME was expanded to include an additional 5,000 people who were diagnosed with M.E./CFS after having Covid-19. This decision came after the Coronavirus pandemic left hundreds of thousands of people in the UK with Long Covid.



We want to see an urgent breakthrough in research that will lead to effective treatments for M.E. – this is only possible with the support of our members and donors. To find out more about how you can donate to investment in high-quality research, please visit www.actionforme.org.uk/donate-online

The ME/CFS Priority Setting Partnership

Elsewhere, the M.E./CFS Priority Setting Partnership continued to go from strength to strength.

In 2021, we entered the next phase. The initiative was made possible by funding from the National Institute for Health Research, the Scottish Government Chief Scientist Office, and the Medical Research Council.

It has been facilitated by the non-profit making initiative, the James Lind Alliance, that uses an approach tried and tested with a range of other neurological conditions including Multiple Sclerosis.

This process was led entirely by people with M.E., carers and health and care professionals, keeping the best interests of the M.E. community as its driving principle throughout.

Thank you to the thousands of people in the M.E./CFS community who participated, ensuring the success of this project and making it one of the most highly engaged-in Priority Setting Partnerships ever.

The PSP in numbers:

- **1,560** responses to the Steering Group's survey, running April to July 2021, from people with M.E., carers and health professionals.
- **5,300** ideas for research were collated as a result.
- **59** summary questions were developed from the key themes raised by these ideas.
- **1,750** people with M.E., carers and health professionals chose their top 10 questions via a survey, running October to December 2021.
- **18** questions were shortlisted by the Steering Group.
- **36** people, representing a broad range of lived experience, took part in three online workshops in March with the aim of finalising the top 10 questions.
- **Top 10+** priority research questions were published in May 2022.

"The Priority Setting Partnership set a record for the numbers of research ideas submitted in the first survey. The commitment and expertise of the steering group was incredibly throughout. All of this demonstrates just how much people with M.E./CFS can and should be part of research"
Toto Gronlund, James Lind Alliance facilitator



Two PhD projects we are funding resumed progress after being delayed by the Coronavirus pandemic.

Joshua Dibble worked with Prof Chris Ponting looked at immune cells (T cells) in people who have M.E.

"There were two components to my PhD," Joshua explains. "The first investigated immune cells from people with severe or mild/moderate M.E., or Multiple Sclerosis, or healthy controls. Unfortunately, the analysis failed to detect any immune activation differences between the groups.

"The second project's result is more promising – I found a statistically significant association between men with M.E. and a gene that is expressed in brain tissue and associated with movement disorders. This result is very preliminary, and will require replication in a separate cohort, however we are already considering potential future research projects in this area."

Marissa Amato has been working at the University of Sussex alongside Prof Neil Harrison, where they used imaging to better understand brain inflammation in people with M.E.

"They had a higher level of inflammatory markers in the blood at baseline compared to controls but were not more sensitive to the inflammatory challenge," says Marissa. "This study provides further evidence of baseline immune disturbances in M.E." This includes evidence of abnormalities in mitochondrial ATP processing, the way the body makes energy, and raised inflammatory markers, partly associated with underlying symptoms experienced by people with M.E.

However, despite evidence of baseline differences, there was no evidence suggesting that people with M.E. who took part in the study were more sensitive to inflammatory challenges.

Joshua's and Marissa's findings add to our ever-growing knowledge base about M.E., which we are continuing to build on.

Shaping our future together: the next five years

Our 2022 - 2027 strategy, *Shaping our future together*, has been developed in partnership with children, young people and adults with M.E., their loved ones and carers, and others who share our values and ambitions. It includes learning from our services, surveys, consultations, workshops and discussion groups, and from wider engagement with the M.E. community.

Shaping our future together sets out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with M.E. Each one is underpinned by our commitment to reaching underserved communities, so they have better access to healthcare, information and services.

Along with improved care and effective treatments, we support a national strategy for M.E. led by the UK government with a clear implementation plan and outcome measures, overseen by a national lead for M.E. This must include a specific research strategy with increased investment leading to validated treatments and, one day, a cure.

We will not stop until we end the ignorance, injustice and neglect experienced by children and adults with M.E.

We are wholly reliant on the generous support of our funders, members and donors to achieve our ambitions for people with M.E. If you would like to find out more about how you can help, please visit www.actionforme.org.uk/support-us

Ambition 1
The lives of people with M.E. are improved by effective access to the information, support and advocacy they need.





Ambition 2
The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence (NICE) guideline for M.E. being effectively implemented across NHS services.

Ambition 3
Increased funding for high-quality research by more researchers leads to effective treatments for M.E.





Ambition 4
The UK Government establishes and leads a national strategy for M.E.

Working collaboratively, and with your support, we are making progress

Compared to the first quarter of last year, our Information and Support team have responded to **17% more emails and phone calls**, and are signposting to sources of specialist help and advice three times as much.

After accessing our new Listen to M.E. helpline, launched in May, **100% of callers who completed our user survey said they felt less isolated** and that their wellbeing had improved. Listen to M.E. helpline is staffed by trained volunteers who are here for anyone affected by M.E., to listen with empathy and understanding (if a caller needs information or resources, they are directed to our Information and Support service). One volunteer told us:

"Volunteering is going to give me the opportunity to use my own experience of living with M.E. to be able to help and support others. I really hope I can offer my understanding to help others not feel so alone."

This work has been made possible by an award from Postcode Local Trust, a grant-giving chartity funded by players of the People's Postcode Lottery.

In April, we published an updated edition of the essential guide, ***Severe ME/CFS: A Guide to Living*** by the late Emily Collingridge, a patient with more than 12 years' experience of severe M.E., working closely with Emily's mother, Jane, and her friends, Naomi and Victoria.

In May, Anna's Blue Sunday Tea Party 2022 raised £9,956 for national and international M.E. charities, including Action for M.E.

Anna says: "Having had the pleasure of working with some of the Action for M.E. team through DecodeME. it is clear how passionate every member of the team is, not only about supporting people with M.E but also about **furthering research, changing attitudes, and bettering the lives of M.E sufferers and their families**."

In June, following the publication of the M.E./CFS Priority-Setting Partnership report, we launched **two PhD-level research projects**. One is with University of Oxford (part-funded by Action for M.E., with the other 50% raised through crowdfunding), the other with King's College London, jointly funded with ME Research UK.

Chair and Trustee of ME Research UK, Jonathan Davies, says: "We believe that future progress in understanding M.E./CFS lies in research, and **the future of research depends on investing now in scientists at the beginning of their careers**."

More than 80 people with M.E. had the chance to gain self-advocacy skills and specialist knowledge to navigate challenges with housing and employment, though our **free, online advocacy webinars** in July and August. One said: "It was nicely paced and the interaction was just right. It would be great to have webinars like this for every aspect of M.E. self advocacy. Having real people to answer questions is very useful."

But perhaps the most significant step towards a new future for people with M.E. came on World ME Day on 12 May 2022, with the Department of Health and Social Care's pioneering statement on M.E.

Ministers set out plans for a new **cross-Government Delivery Plan on M.E.** for England, aligning with other devolved nations of the UK. The statement, made to Parliament by Health Minister Lord Kamall, is the first time that Government has made an **explicit and dedicated statement on M.E.**

With work on this well underway, it is fantastic to see that this devastating condition is being explicitly acknowledged by Government as a priority. Through greater partnership working we hope to able to better understand M.E. with the aim of finding effective treatments and ultimately a cure.

Want to shape the future with us?
You can learn, donate, volunteer, share your view or get support now at www.actionforme.org.uk







How we raised and spent our income this year

In response to the rising demand for our services and increased focus on M.E., we are committed to continuing to strengthen our financial position and achieve the levels of income and efficiency we need to end the ignorance, injustice and neglect experienced by adults and children with M.E.

Our **recorded total income** for the year was £2.5million, up 110% from the previous year. This is largely due to an exceptional legacy of £1.3million that has seen the charity record a total income of over £2 million for the first time.

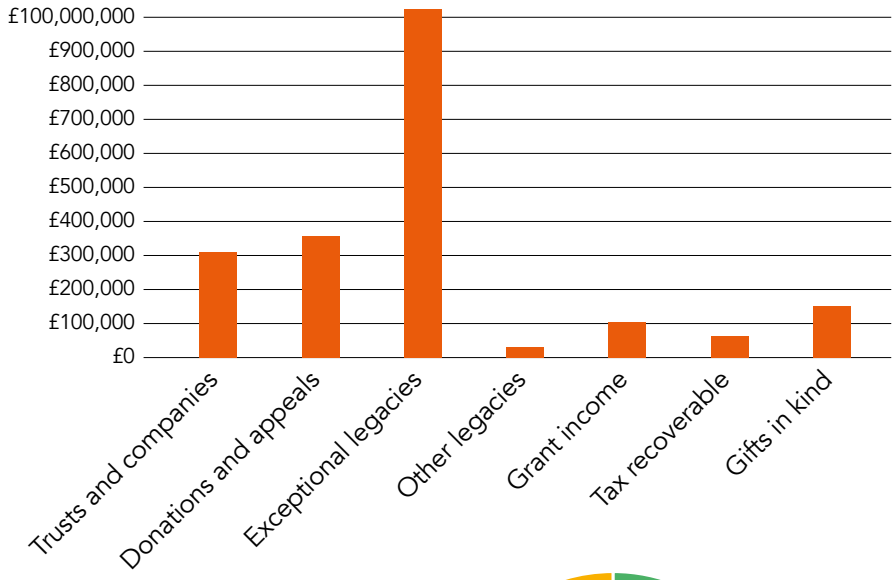
Overall expenditure was £1.3million, an increase of 59% from the previous year as a result of increased expenditure on frontline services, designation for increased collaborative biomedical research activity, and planned increases to the staff team to put the charity in a strong position to deliver our ambitious new strategy for 2022-27.

The **net result** is a surplus (before net losses from investment) of £1.2million. Thanks to the exceptional legacy received our current reserve position is well ahead of the Trustee target.

In our statement of strategic intent, we promised to improve healthcare and information for people with M.E.

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. Our income was considerably higher this year due to the exceptional legacy received in the last quarter of the year, £1.1million, of which has been designated by the Board of Trustees to deliver charitable activities within our new five-year strategy (2022 – 2027).

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 (61%) of our total gross expenditure is on staff salaries (including employer National Insurance and pension contributions). We increased the number of front line staff during this year by 2.5FTE due to the increased demand for our services.



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

During 2021 – 2022, **we raised £4.20 for every £1** invested in fundraising (excluding the income from the exceptional legacy).





This year, we spent:
£657,366 on our information, advocacy and peer support services for adults, young people and families with M.E.
£176,582 on our campaigning and influencing work
£248,961 on our investment in collaborative biomedical research
£243,249 on fundraising (cost of generating voluntary income at £240,503, plus goods and trading at £2,746).

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 to 14.

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 Director of Business Support & Development (previously the Operations Director), 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 Policy Group 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.
- 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 targets 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 2021). 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 education professionals, government and senior officials, and other decision-makers. As a member of a number of organisations and alliances, including Forward M.E., 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.

We also provide secretariat support to the UK CFS/M.E. Research

Our people, structure and governance

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 36. 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 always be protected, and the trust of our supporters must not be violated. The policy also sets out the way in which we deal with fundraising complaints.

Risk

The Director of Business Support & Development 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 to protect the quality of our work, reputation and income.

The largest risks facing our charity are a significant drop in income affecting our ability to provides 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 2021 – 2022.



Financial review

Statement of financial activities

We are the only M.E. charity in the UK providing direct support to both adults and children. As the UK emerged from the lockdowns and other Covid-19 restrictions of the previous year, our charity started the year on a firm financial footing having taken decisive action in 2020/21 to safeguard the future sustainability of the organisation. This included implementing a restructure and reducing our staff team by 40%.

However, there remained significant external uncertainty related to the pandemic, not least how many people who had caught Covid-19 would go on to develop M.E. as seen during the SARS and MERS epidemics. In response to this shifting landscape, instead of developing another five-year strategy, the charity developed a one-year Statement of Strategic Intent to enable it to continue to deliver vital services to people affected by M.E., campaign for change and increase much-needed research into the condition, while remaining flexible and able to adapt and respond to the post-Covid landscape.

In June 2021 our board of Trustees began talks with the Trustees of The ME Trust, with a view to merging our organisations to increase the availability of holistic health and support services to people with M.E. and their families/carers. This merger was successfully completed on 1 February 2022 and upon merging we transferred residual funds of £18k from The ME Trust bank account to Action for M.E.

Our annual Big Give Christmas Challenge fundraising campaign was successful for the fifth year running, raising £133,804 in income to support our services, medical education and collaborative research work. Legacies significantly outperformed expectations this year, and in addition to the exceptional legacy of £1.3million, we received other legacies totalling £31k.

Overall expenditure was £1.3million. We have significantly strengthened our ability to support people with M.E. through investment in our staff team, including significant investment in the roles delivering frontline services to people with M.E. Our staff team increased from 19FTE to 29FTE during the period covered by this report, including 1FTE new employees as a result of merging with The ME Trust.

At year-end, general reserves were £736k (up £468k). In addition, the charity has designated reserves of £1.1million.

Restricted reserves were £252k (down £26k) which will be expended over the course of the next year on service delivery, biomedical PhDs and the Clare Francis Research Fellowship. 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 surplus realised this year has significantly increased our accumulated funds and cash reserves at the year-end.

Funding sources

The principal funding sources for Action for M.E. are charitable trusts, legacy giving, community fundraising and events, Supporting Membership income and individual gifts. Other funding sources are Gift Aid and Christmas card sales.

We are fortunate to have a broad and diverse fundraising base which means we are not overly reliant on one source of income. In order to maintain and increase our income diversity, as part of our new five-year strategy, we will be investing further in our fundraising team to help us secure long-term income.

This year, we are enormously grateful to The Jonathan Swire (1989) Charitable Trust, the De Laszlo Foundation, BBC Children in Need, The Postcode Lottery Trust, The ScottishPower Foundation, Sir James Reckitt Charity, National Lottery Community Fund Awards for All, the Garfield Weston Foundation and Scottish Government (Neurological Support Framework Funding 2021-22) 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 currently has £50,000 invested in the M&G Charibond fund.

Reserves policy

The current policy is to maintain the level of 'free' (unrestricted) funds at no less than four times, and no more than six times, the monthly unrestricted running costs of the charity.

The charity ended the financial year with 23.4 months of unrestricted reserves (£1.8m) and 6.8 months (£526,116) when excluding the exceptional legacy. This is based on an average monthly unrestricted expenditure rate of £77,033.

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 statements for each financial year.

Under company law, the Trustees

Financial review

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.

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 judgments 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 time, the financial position of the charity and enable them to ensure that the 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 (previously known as Moore–Stephens) was re-appointed as our auditor at the 2021 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 audit 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.



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 20 September 2022

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 2022 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 2022 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 16, 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.

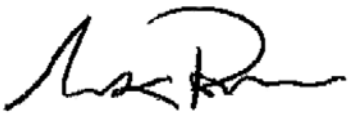
Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

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 September 2022

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2022

	Notes	Unrestricted funds (£)	Restricted funds (£)	Total 2022 (£)	Total 2021 (£)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	1,981,672	306,713	2,288,385	999,106
Other trading activities	3	64,158	62,176	126,334	111,320
Investment income	4	1,058	–	1,058	301
Incoming resources from charitable activities	3	74,947	6,994	81,941	81,400
Total incoming resources		**2,121,835**	**375,883**	**2,497,718**	**1,192,127**
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	240,503	–	240,503	114,849
Fundraising trading: costs of goods sold and other costs		2,746	–	2,746	960
Charitable activities	5	681,143	401,766	1,082,909	716,785
Total resources expended		**924,392**	**401,766**	**1,326,158**	**832,594**
Net gains/(losses) on Investments		**(2,249)**	**–**	**(2,249)**	**–**
Net movement in funds	12	1,195,194	(25,883)	1,169,311	359,533
Reconciliation of funds					
Fund balances at 1 April 2021		608,050	277,465	885,515	525,982
Fund balances at 1 April 2022		**1,803,244**	**251,582**	**2,054,826**	**885,515**

All incoming resources and resources expended derive from continuing operations. The notes on p 25 to 35 form an integral part of these accounts.

Balance sheet

As at 31 March 2022 (company registered number 2906840)

	Notes	2022 (£)	2021 (£)
Fixed assets			
Tangible assets	9	27,423	27,679
Investments	10	47,751	50,000
Total fixed assets		**75,174**	**77,679**
Net current assets			
Debtors	11	1,056,440	192,832
Cash at bank and in hand		1,042,512	689,256
Total current assets		2,098,952	882,088
Creditors: Amounts falling due within one year	12	(119,300)	(74,252)
Net current assets		1,979,652	807,836
Total assets less current liabilities		**2,054,826**	**885,515**
Capital and reserves			
General funds		736,244	268,050
Designated funds	13	1,067,000	340,000
Unrestricted funds		1,803,244	608,050
Restricted funds	14	251,582	277,465
Accumulated funds		**2,054,826**	**885,515**

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 24 to 34 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 7 September 2022

Action for M.E. cash flow statement for the year ended 31 March 2022

		2022	2021
Net cash flow from operating activities	See note a below	365,060	329,269
Net cash flow from investing activities	See note b below	(11,804)	(61,821)
Net increase in cash and cash equivalents		353,256	(267,448)
Cash and cash equivalents at beginning of period		689,256	421,808
Cash and cash equivalents at end of period		1,042,512	689,256

Notes to the cash flow statement

a Cash flows from operating activities

	£	£
Net movement in funds	1,169,311	359,533
Depreciation	13,118	11,624
(Gains)/losses on investments	2,249	–
Financial income	(1,058)	(301)
	1,183,620	370,856)
(Increase)/decrease in debtors	(863,608)	(62,795)
(Decrease)/increase in creditors	45,048	21,208
NET CASH FROM OPERATING ACTIVITIES	365,060	329,269

b Cash flows from investing activities

	£	£
Purchase of tangible fixed assets	(12,862)	(12,122)
Interest received	1058	301
Investment in financial assets	–	(50,000)
NET CASH FROM INVESTING ACTIVITIES	(11,804)	(61,821)

Analysis of changes in Net Funds

	At 01.04.2021 (£)	Cash Flow (£)	At 31.03.22 (£)
Cash at Bank	689,256	353,256	1,042,512
Total	**689,256**	**353,256**	**1,042,512**

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 34. 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 no 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.

Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes. Designated funds comprise unrestricted funds that have been set aside by the Trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the accounts. Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The aim and use of each restricted fund is set out in the notes to the accounts.

Deferred Income

In accordance with the FRS 102 SORP issued by the Charity Commission for England and Wales and the Office of the Scottish Charity Regulator, grants received in advance and specified by the donor as being subject to specific terms and conditions are deferred until the conditions applying to the grant are within the control of the Charity and it is probable that the imposed terms and conditions can be met. Such deferrals are shown in the notes to the accounts and the sums involved are shown as creditors in the accounts.

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 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 or 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 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 in order to write off the cost of the assets (less their expected residual value) over their estimated useful economic lives. Office Equipment – 25% on 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 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 £18,566 (£24,008 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. This year the charity has been notified of an exceptional legacy accrued at 90% of the legacy asset list value.

3 Details of incoming resources

	Unrestricted funds (£)	**Restricted funds (£)**	**Total 2022 (£)**	Total 2021 (£)
Donations and legacies				
Trusts and companies	161,241	145,929	**307,170**	253,828
Donations and appeals	318,866	45,625	**364,491**	353,422
Exceptional legacies	1,277,128	–	**1,277,128**	–
Other legacies	31,000	–	**31,000**	127,924
Grant income	9,400	91,224	**100,624**	193,333
Tax recoverable	55,887	6,130	**62,017**	67,399
Gifts in kind	128,150	17,805	**145,955**	3,200
	1,981,672	**306,713**	**2,288,385**	999,106
Other trading activities				
Lotteries and raffles	10,452	–	**10,452**	11,889
Christmas cards	10,452	–	**10,452**	11,889
Supplement commission	2,372	–	**2,372**	2,588
Merchandise	2,372	–	**2,372**	2,588
Events	–	–	**–**	–
Other	45,861	62,017	**107,878**	93,937
	64,158	**62,176**	**126,334**	111,320
Incoming resources from charitable activities				
Subscriptions	74,929	–	**74,929**	81,377
Healthcare services	–	6,994	**6,994**	–
Information and publications	18	–	**18**	23
	74,947	**6,994**	**81,941**	81,400

Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy for work related to charity merger, Ph.D. contracts has been valued at £127, 855 based on number of hours worked. Other Gifts in Kind include funds brought over as a result of a merger and restricted to healthcare services.

Details of 2021 income	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)
Donations and legacies			
Trusts and companies	104,406	149,422	253,828
Donations and appeals	326,027	27,395	353,422
Legacies	114,042	13,882	127,924
Tax recoverable	63,360	4,039	67,399
Gifts in kind	3,200	–	3,200
Grant Income	10,000	183,333	193,333
	621,035	**378,071**	**999,106**
Other trading activities			
Lotteries and raffles	11,899	–	11,899
Christmas cards	2,602	–	2,602
Supplement commission	2,588	–	2,588
Merchandise	163	141	304
Other	18,315	75,622	93,937
	35,557	**75,763**	**111,320**
Incoming resources from charitable activities			
Supporting Membership	81,377	–	81,377
Healthcare services	–	–	–
Information and publications	23	–	23
	81,400	**–**	**81,400**

4 Investment income

	2022 (£)	2021 (£)
Interest from cash investments in the UK	**1,058**	**301**
	1,058	**301**

5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2022 (£)	Total 2021 (£)
Costs of generating voluntary income				
Staff costs	46,777	–	**46,777**	13,965
Direct fundraising costs	13,967	–	**13,967**	11,102
Support costs – see below	179,759	–	**179,759**	89,782
	240,503	**–**	**240,503**	**114,849**

	Unrestricted funds (£)	Restricted funds (£)	Total 2022 (£)	Total 2021 (£)
Charitable activities				
Information and support services	420,299	237,067	**657,366**	462,196
Campaigning and influencing work	176,582	–	**176,582**	106,926
Collaborative biomedical research	84,262	164,699	**248,961**	148,293
	681,143	**401,766**	**1,082,909**	**716,785**

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

	Activities undertaken directly	Support costs as below	Total (£)
Activity			
Information and support services	86,902	333,397	**420,299**
Campaigning and influencing work	86,702	89,880	**176,582**
Collaborative biomedical research	–	84,262	**84,262**
	173,604	**507,539**	**681,143**

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 £
Support costs						
Information and support services	17,587	31,550	19,354	242,744	22,162	**333,397**
Campaigning and influencing work	4,741	8,505	5,218	65,441	5,975	**89,880**
Research	4,445	7,974	4,891	61,351	5,601	**84,262**
	26,773	48,029	29,463	369,536	33,738	**507,539**
Fundraising	9,483	17,011	10,435	130,881	11,949	**179,759**
	36,256	**65,040**	**39,898**	**500,417**	**45,687**	**687,298**

Office costs include £128,183 (£3,200 in 2021) for professional services in kind.

	2022 (£)	2021 (£)
Governance costs		
Administrative salaries – based on time spent	**25,548**	22,400
Indemnity insurance for Trustees	**2,287**	1,744
Governance training	**–**	1,320
Trustees' expenses	**476**	–
Auditors' fees	**6,900**	6,400
Design and printing	**880**	756
Postage and office supplies	**165**	32
	36,256	30,646

	2022 (£)	2021 (£)
Grant activities		
The University of Sussex – PHD in biomedical research	**–**	15,664
	–	15,664

Details of 2021 expenditure	Unrestricted funds (£)	Restricted funds (£)	2021 (£)
Costs of generating voluntary income			
Staff costs	13,965	–	**13,965**
Direct fundraising costs	11,102	–	**11,102**
Support costs – see below	83,792	6,000	**89,782**
	83,792	**6,000**	**89,782**
Charitable activities			
Information and support services	193,908	268,288	462,196
Campaigning and influencing work	103,329	2,967	106,296
Collaborative biomedical research	32,856	115,437	148,293
	330,093	**386,692**	**716,785**

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

	Activities undertaken directly	Support costs as below	Total (£)
Activity			
Information and support services	87,126	106,782	**193,908**
Campaigning and influencing work	70,473	32,856	**103,329**
Collaborative biomedical research	–	32,856	**31,856**
	157,599	**172,494**	**330,093**

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 £
Support costs						
Communications and policy	3,929	4,443	3,338	17,902	3,244	**32,856**
Information and services	12,769	14,440	10,849	58,182	10,542	**106,782**
Research	3,929	4,443	3,338	17,902	3,244	**32,856**
	20,627	23,326	17,525	93,986	17,030	**172,494**
Fundraising	10,019	11,330	8,512	45,650	8,271	**83,782**
	30,646	**34,656**	**26,037**	**139,636**	**25,301**	**256,276**

6 Net movement in funds

	2022 (£)	2021 (£)
This is stated after charging:		
Operating lease	**31,838**	18,430
Depreciation of owned fixed assets	**13,118**	11,605
Auditor remuneration	**6,900**	6,400
Trustees' expenses	**476**	–
Pension costs	**49,200**	**36,435**

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 £2,038 (in 2021 it was £1,744).

7 Staff costs and emoluments

	2022 (£)	2021 (£)
Gross salaries	**733,254**	543,595
Employer's National Insurance	**55,975**	45,857
Pension contributions	**22,771**	18,440
	812,000	607,892

Numbers of full-time employees or full-time equivalents		
	2022	2021
Engaged on charitable activities	**18**	11
Engaged in fundraising activities	**6**	4
Engaged on management and administration	**5**	4
	29	**19**

The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:	**Number**	Number
	1	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 £89,733 (£87,391 in 2021).

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

	2022 (£)	2021 (£)
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.	**476**	–
Amounts of expenses incurred by Trustees that were donated back to the Charity.	**280**	–
There were no related party transactions up to 31 March 2022.		

9 Tangible fixed assets

	Office equipment (£)
Cost	
At 1 April 2021	66,897
Additions for year	12,862
Disposals in year	–
At 31 March 2022	**79,759**
Depreciation	
At 1 April 2021	39,218
Charge for year	13,118
Disposals in year	–
At 31 March 2022	**52,336**
Net book value	
At 31 March 2021	27,679
At 31 March 2022	**27,423**

10 Investments

Market value	
At 1 April 2021	50,000
Revaluations	(2,249)
At 31 March 2022	47,751
Net book value	
At 31 March 2021	50,000
At 31 March 2022	**47,751**

There were no investment assets outside of the UK.

11 Debtors

	2022 (£)	2021 (£)
Trade debtors	**66,741**	41,397
Prepaid expenses	**23,986**	28,911
Due from HMRC	**11,228**	–
Accrued income	**954,485**	122,524
	1,056,440	192,832

12 Creditors: amounts falling due within one year

	2022 (£)	2021 (£)
Trade creditors	**63,403**	43,054
Accrued expenses	**32,263**	15,178
Unpaid pension contributions	**5,258**	3,482
Due to HMRC	**–**	897
Other taxation and social security costs	**18,376**	11,641
	119,300	74,252

13 Funds

	General funds (£)	Designated funds (£)	Total (£)
Statement of unrestricted funds			
Balance at 1 April 2021	268,050	340,000	**608,050**
Transfer between funds	(727,000)	727,000	**–**
Surplus for year	1,195,194	–	**1,195,194**
Balance at 31 March 2022	**736,244**	**1,067,000**	**1,803,244**

	Tangible fixed assets (£)	Cash	Other Net current assets (£)	Total (£)
Analysis of net assets between funds – current year				
Unrestricted funds:				
General funds	75,174	630,531	30,539	736,244
Designated funds	–	242,000	825,000	**1,067,000**
	75,174	872,531	855,539	**1,803,244**
Restricted funds	–	169,981	81,601	**251,582**
	75,174	1,042,512	937,140	**2,054,826**

	Tangible fixed assets (£)	Cash	Other Net current liabilities (£)	Total (£)
Analysis of net assets between funds – prior year				
Unrestricted funds:				
General funds	26,679	137,344	103,027	**268,050**
Designated funds	–	340,000	–	**340,000**
	27,679	477,344	103,027	**608,050**
Restricted funds	–	211,911	65,554	**277,465**
	27,679	689,255	168,581	**885,515**

14 Restricted funds

	Opening balances £	Incoming resources £	Outgoing resources £	Closing Balances £
Movements in restricted funds				
Research	147,746	50,948	34,428	**164,266**
Priority Setting Partnership	65,554	–	65,554	**–**
DecodeME	–	62,017	62,017	**–**
Information and Support Service	51,979	37,010	70,995	**17,994**
Learn about M.E.	–	31,358	20,671	**10,687**
M.E. Advocacy	–	59,866	21,930	**37,936**
Advocacy Services	–	74,698	72,940	**1,758**
Breaking Isolation	2,480	8,219	9,328	**1,371**
Healthcare Services	–	30,855	30,855	**–**
M.E. Friends Online	4,828	10,000	6,279	**8,549**
Listen to M.E.	–	10,912	6,769	**4,143**
Printed resources	4878	–	–	**4,878**
	277,465	**375,883**	**401,766**	**251,582**

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

Priority Setting Partnership – funding to manage and administrate this project led by people with M.E., carers and clinicians, and facilitated by the James Lind Alliance, which aims to influence future M.E. research funding.

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. Read more on p 6.

Learn about M.E. – funding from the Scottish Government's Neurological Framework to promote a free online learning module for GPs, medical students and allied health professionals, working with 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.

Healthcare Services – funding for our Doctor, Physiotherapy, Counselling and Chaplaincy services, offering individually tailored whole-person care, and launched following our merger with UK charity The ME Trust in February 2022. Read more on p 6.

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 £5,258 (£3,482 in 2021) 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 2022 (£)	Total Leases 2021 (£)
Operating lease payments falling due:		
within one year	30,895	30,895
within two to five years	122,440	122,440
over five years	30,326	53,070
	183,661	**206,405**

17 Contingent assets

During the year the Charity has been advised of a number of legacies and has received significant income. 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 £255,000 of which £60,000 is to be spent in the year to 31 March 2023.

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

Trustees and Directors 2021 – 2022

President

Clare Francis MBE

Vice President

Martin Arber

Patrons

Lord Bragg
Julie Christie
Lord Puttnam CBE
Alan Cook CBE
Prof Anthony J Pinching

Honorary Patron

Ondine Upton

Ambassador

Jennie Jacques

Board of Trustees

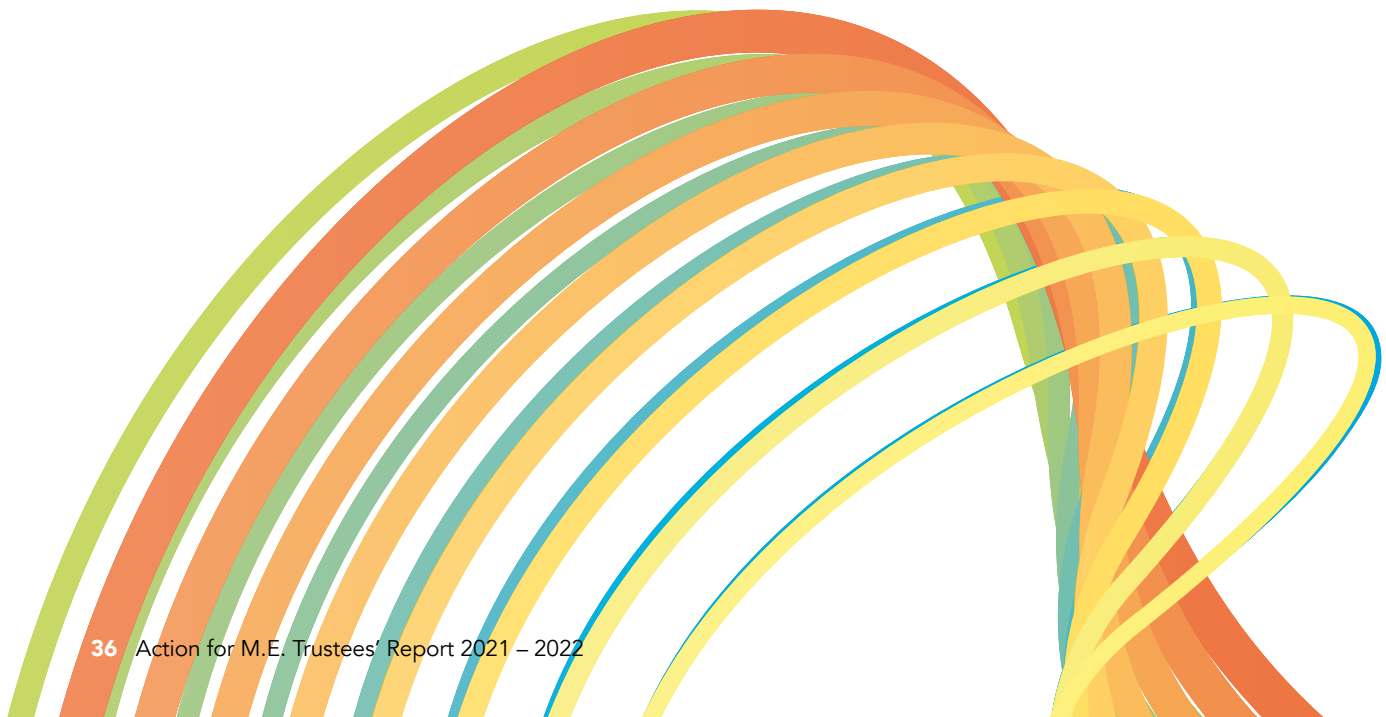
Roger Siddle, Chair
Jonathan Manuel, Treasurer
Colin Batten
Philip Courtney
(joined February 2022)
Shaun De Boo
Alison Deeth
(stood down October 2021)
Julianne Devine
(joined February 2022)
Lucy Goodwill
Sue Hardy
Rollo Hope
(joined February 2022)
David Leigh
Philip Marsden
(stood down October 2021)
Phil Murray
(stood down October 2021)
Jane Stacey
Ed Stephens
Matt Symonds

Chief Executive

Sonya Chowdhury

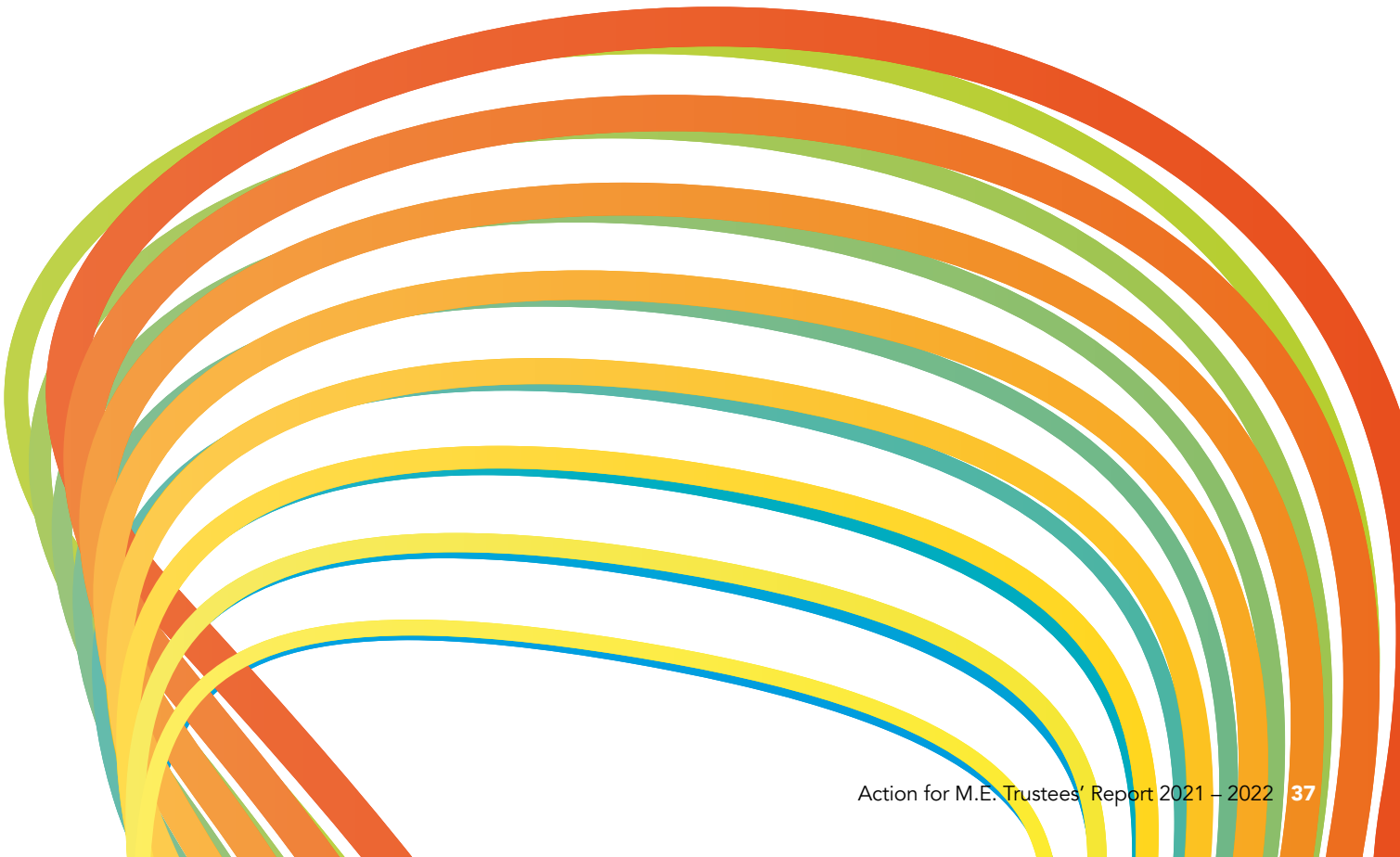
Principal Medical Adviser

Dr David Strain



"Always very appreciative of Action for M.E. and how they respond on the rare occasions I ask for support. Wish there wasn't a need for your help but been a long-term member and will be remaining so. Thank you all for everything you do (fundraising, advocacy, support, research, arguing our case when we can't, newsletters and the list goes on) to support those of us who are ill (and carers)."

Action for M.E. supporter





WANT TO SHAPE THE FUTURE WITH US?

Learn, donate, volunteer, share your view or get support now at

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ACTION FOR ME

England & Wales - Charity number 1036419

Accounts

Action for M.E. Trustees' report

2020 – 2021



action for m·e

Lifeline through lockdown…

The last year has been incredibly tough for everyone worldwide, and we have seen how life has become even harder for people with M.E.

Colleagues have been providing support to people in very distressing and complex situations due to the pandemic; we have been inundated with enquiries and concerns regarding vaccinations; and we have sadly seen an increase in the number of people being diagnosed with M.E. following Long Covid.

Our Crisis, Support and Advocacy Service, launched in April 2020 in direct response to increased need, responded to 1,754 enquiries and offered long term support to 221 people, sometimes over many months. Over this past year, because of the generous input from our supporters and donors, we have significantly grown the service from seven staff members to 10. We know that we have more to do: there are still waiting lists for advocacy support and we must do more to reach currently under-served communities, especially people from Black, Asian and other ethnic minorities.

In contrast, we have heard of young people who are finally able to access education without having to use limited energy on getting into school, and people who have been able to manage some level of employment, as a result of our lives moving more online. While we know that not everyone is able to get online due to symptoms or where M.E. is more severe, it has helped some.

While ensuring we support people now, we have continued to work to secure change for the future. In September 2020, we commenced work on the world's largest M.E. DNA study, DecodeME. With £3.2 million funding, we are co-leading this study with Prof Chris Ponting and colleagues at the University of Edinburgh, people with M.E. and carers. The involvement of people with lived experience of M.E. has led to significant changes in the study's design and we are proud to be a part of this ambitious partnership. We need to recruit 20,000 people with M.E. in the UK, over the age of 16, who meet quite strict research criteria. With recruitment opening in autumn 2021, we have a lot to do and, with the help of the M.E. community, I am confident we will achieve this.

In Spring 2022, we will be reporting the top 10 M.E. clinical research priorities, as identified through wide consultation. Our funding has enabled us to set up a Steering Group of people with M.E., carers and clinicians who have led this M.E./CFS Priority Setting Partnership using a tried and tested methodology pioneered and overseen by the James Lind Alliance. This approach has transformed research in other disease areas and we will work with the community, clinicians, researchers and funders to secure the same for M.E.

New strategy

Throughout this year, we have been working on a new strategy which will provide the framework for all our work. You can read more about this later in the report.

We support people through our services while also lobbying for change. This cannot be done without funding and the skills, expertise and insight that our supporters provide free of charge to help us do more and do better. There are too many to name, but we thank each and every one of you alongside our Board of Trustees and volunteers who generously give their time, energy and expertise.

There are many ways you can get involved and help end the ignorance, injustice and neglect experienced by people with M.E. Here are three ways that you might be able to consider.

- Providing services and lobbying for change cannot be done without funds. Donations, fundraising and other support that enables us to increase our networks of potential donors is critical. **Find out more at www.actionforme.org.uk/make-a-difference**

- Money is essential – but so is amplifying our voice and reaching people outside our current network. Sharing our content online, writing to your MP, MSP, AM or local media, or talking to other people about M.E. and its impact, all help raise awareness. **Join our Act4ME Network at www.actionforme.org.uk/Act4ME**

- We need your help in recruiting 20,000 people for the DecodeME study. Helping us reach this goal quickly means we can move one step closer to understanding more about the illness. Our aim is to enable development of targeted treatments and one day find a cure, so our vision of a world without M.E. becomes a reality. We do not know what the future holds but we are committed, as always, to working collaboratively, effectively and with determination to ensure that we are here when people need us. **Get involved at www.decodeme.org.uk**

We can only do what we do with your support. Thank you.



Sonya Chowdhury (pictured right)
Chief Executive
Action for M.E.

...Leader for change

It has been a difficult year in lots of ways but also one that has provided opportunity and hope. Over the past year, we have changed what we do and how we do it to respond to the changing world around us. We responded robustly to the uncertainties created by the pandemic, refocusing our capacity and resources to increase and expand our support, and also to ensure a good financial position for the future.

Thanks to the work of our team and the incredible support from our donors and community, we have seen the organisation go from strength to strength. We have worked hard to ensure that we continue to increase our funds despite the fundraising environment becoming more challenging for many, not least with regular fundraising opportunities such as runs and marathons being postponed or cancelled as a result of the pandemic.

With the move to digital fundraising, we were delighted to see a number of fundraisers join our Chief Executive in the national 2.6 Campaign in place of the London Marathon. Our income was 26% higher at the end of the financial year than we had budgeted.

As a direct result, we have been able to expand our support services, recruiting more people to help us provide more hours and be there to support more children, young people, adults and families living with M.E. There were also other very notable successes in the year – not least the launch of DecodeME and the instigation of the M.E./CFS Priority Setting Partnership.

We know, however, there is more to do – demand for our services is higher than we can currently meet, and we are not immune to the challenges of offering continuing support when our own team face the demands of lockdown and home working. We need to address this, but also to decide on our other priorities for the years to come. As a Board of Trustees we decided that, in the light of ongoing pandemic uncertainty, it would be unwise to attempt to define an explicit strategy for the charity for 2021 – 2026. We have, though, agreed some broad areas of direction on which we will focus, and you can read more about these on p 12-13.



Roger Siddle (pictured below)
Chair of Board of Trustees
Action for M.E.





"We have been able to expand our support services, recruiting more people to help us provide more hours and be there to support more children, young people, adults and families living with M.E."

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On the cover (clockwise from top left):

Dr Nina Muirhead presenting at the UK CFS/M.E. Research Collaborative Conference we organised.

11-year-old **Sonny** set himself the challenge to raise £100 for us by cycling 100 miles in stages, because his mum Emma has M.E. – his final fundraising total was nearly six times that.

Alex shared pictures of herself on a good M.E. day, and a bad M.E. day, for our Big Give Christmas Challenge. "I'm mainly housebound/bedbound, a lot of people don't understand how one day you can look 'healthy' and the next you can look terrible."

Action for M.E.'s Fundraising Officer **Josh** took on the Prudential RideLondon Free Cycle challenge in support of his brother, who has M.E.

Bethany shared her story with us for M.E. Awareness Month. She told us: "Action for M.E has made me feel recognised and heard. The stories and research keep me optimistic and aware that I am not alone."

We co-lead DecodeME, the world's largest DNA M.E. study, with **Prof Chris Ponting**, University of Edinburgh.

Naomi works with us to increase understanding of severe M.E., and contributes to our *InterAction* membership magazine.

Our year in numbers



1,754

enquiries responded to through our Crisis, Support & Advocacy Service:

80% increased understanding of their rights and options

78% increased their knowledge of support available



168

families supported through our services for children and young people:

75% have increased understanding of their rights and options

75% felt more confident communicating with professionals



214 downloads of our first Learn About M.E. podcast

600 health professionals completed the CPD-accredited M.E. learning module accompanying the podcast

239,450

people found information and support on our website

10,300

downloads of our booklets, factsheets and support resources





53

adults with M.E. supported long-term through our Advocacy service:

100% satisfaction with the service received

91% reported improved health and wellbeing

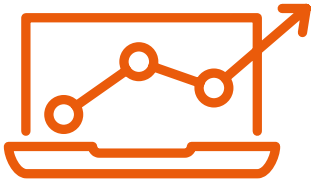
Feedback from clients:

"I felt a weight had been lifted by the advice and support given. Thank you."

"Before I was completely clueless. I can't thank you enough. You have put my mind at ease, enabled me with tools to use to manage my condition and how to navigate communication with healthcare professionals. This service is invaluable. Thank you so much."

31,308

sign ups to DecodeME project by March 2021



1,500

is the number of people with M.E. carers and supporters we facilitated to have their say on the draft guideline for M.E from the National Institute for Health and Care Excellence, challenging some areas of the guideline and endorsing others.



We responded to two public House of Commons Select Committee enquiries calling for lessons to be learnt from the pandemic. We highlighted the difficulties people experienced in securing food and the inequality experienced by people with a disability during the pandemic.



£169,710

raised through our Big Give Christmas Challenge – our most successful year ever and we won an award and additional funding for our campaign.

People with M.E. get the information and support they need from us.

In April 2020, many people with M.E. found the services and support they had come to rely on thrown into disarray.

In response, we re-shaped all our services into a single Crisis, Support and Advocacy Service, offering information, practical assistance, emotional support, signposting, and UK-wide advocacy.



In the 12 months that followed, people with M.E. called or emailed us for information, emotional support and practical help

1,754 times.

Many feel isolated as a result of living with M.E. We can signpost to local support groups and our peer-support forums, while those who become Supporting Members tell us that our membership magazine *InterAction* helps them feel more connected and less alone.



A year on, based on client feedback, we have updated our service name to Information, Support and Advocacy. This reflects the fact that, while we are not a crisis/urgent service, our friendly team is still here for people with M.E. of all ages seeking information, support and signposting.

"I wish I had found you years back. Your service was empathetic and understanding as well as well-informed, and brilliant at ascertaining the information required to ensure you gave me the right advice. For the first time in my life when discussing this condition, I feel understood."
June 2020

We work with everyone who gets in touch to:

- break issues down so they feel less overwhelming
- explore priorities and options
- frame questions they want to ask professionals
- share useful resources.



239,450

people came to our website to find the information they needed; they downloaded factsheets, guides and template letters 10,300 times.

Catherine used our template letter to explain why, because of her M.E., she was eligible for priority access to the Covid-19 vaccine. "When the GP called to discuss my letter, we talked through my experiences of M.E. and impact on daily life. Today I just received my first vaccine! I believe this is a direct result of the letter template you provided. She [also] asked if I was under the CFS clinic […] I will now be asking for a referral into this service. Again, this conversation would never have come about if your letter hadn't prompted this discussion."

Nearly a third (31%) of the 1,754 enquiries to our frontline team related to Covid-19; and nearly a third (31%) were prompted by health concerns. Nearly a quarter (23%) of enquiries included questions about applying for welfare benefits, another key challenge facing people with M.E.



- **97%** of clients said they were satisfied with the service received.
- **80%** agreed they had increased understanding of their rights and options.
- **78%** agreed they had increased their knowledge of support available.

"I was really impressed with how quickly I received a reply and also with the amount of help suggested in the reply. Also, it was nice to have someone suggest pacing myself when reading it. After three years of being made to feel like I am pretending to be ill, it is lovely to know people understand what I am going through."
November 2020

We empower and advocate for young people, families and adults living with M.E.

If someone with M.E. needs more detailed, ongoing support, we can refer to our Advocacy and Family Support teams.

"I was supported by a highly skilled advocate who with patience and empathy always helped me to clarify my thinking and to plan things through. With so much foggy brain this has helped immensely. She always sent a clear plan that I could follow broken down in manageable parts and clear goal setting. As the support continued I realised that I felt empowered to continue by myself, but I wouldn't have felt this way without your support."
January 2021

David got in touch in September. He is mostly housebound with M.E., and sleeps in a damp bedroom at a relative's house. He approached social services for help, but found they don't understand M.E. "They just see me being able to walk around when they have met me, not the after effects."

Our Advocacy team worked with David to plan what needs to be done to enable him to move into private rented accommodation, including effectively communicating his needs to letting agents. When his circumstances changed, we agreed to pause the work until he was ready to pick it up again. All our contact with clients is led by them, and done at their pace.



Overall, 53 adults with M.E. were supported by our Advocacy service over the year.

- **100%** said they were satisfied with the service received.
- **91%** reported improved health and wellbeing.
- **91%** improved self-advocacy skills.

Over the year, we supported 168 families of children and young people with M.E. to access medical care and education that meets their needs.

- 75% reported increased understanding of their rights and options.
- 75% told us they felt more confident communicating with professionals.

"Just to let you know their Education and Healthcare Plan (EHCP) has been submitted, we're still awaiting to hear. The information you sent through and your help was invaluable so thank you so much. The school said it was the most comprehensive EHCP they had ever seen."
November 2020

Young people worked to develop a plan for our Breaking Isolation workshops, funded for three years by Children in Need. Over the year, 24 young people took part.



- **66%** reported reduced loneliness.
- **61%** reported increased self-esteem.
- **50%** felt better able to build positive relationships.

"Meeting other young people with M.E. was good and it never felt worrying to be there. It felt good to share stuff about M.E that most "normal people" wouldn't get."
Workshop participant



What next?

We will:

- expand our Information, Support and Advocacy service to meet increasing demand and reduce waiting lists
- increase accessibility to the service
- break isolation through increased peer support services
- increase access to health care/information
- increase access to our work; and increase engagement from currently underserved communities including Black, Asian and other ethnic minorities.



We take action to remedy the ignorance, injustice and neglect still faced by people with M.E.

In November 2020 we were successful in securing Scottish Government Neurological Framework funding for a five month medical education project, in partnership with the ME Association, #MEAction Scotland and Dr Nina Muirhead. The project increased knowledge and understanding of M.E. by health professionals, through dissemination of Dr Muirhead's CPD-accredited learning module and an accompanying podcast. Over 600 professionals – including 200 from Scotland – completed the module during the duration of the project, and our Learn About M.E. podcast was downloaded 214 times.

Of the health professionals who completed the module:

- **100%** reported improvement in patient-centred care and patient pathways.
- **77%** reported increased confidence in treatment and management of M.E.
- **75%** reported increased confidence in diagnosis of M.E.

"This module was concise, informative, and provided evidence-based explanations. It has greatly helped my understanding of diagnosis and management of M.E./CFS, and the guidance on post-exertional malaise and chronic post viral fatigue is likely also to be very applicable to patients with Long Covid."
Dr Shaun Peter Qureshi, Edinburgh

We facilitated 1,500 people with M.E., carers and supporters to have their say on National Institute for Health and Care Excellence (NICE)'s draft guideline for diagnosing and managing M.E. via our detailed survey.

We asked which elements of the draft NICE guideline were most important to them; the majority of respondents said it was the clear advice that people with M.E. should not be offered any therapy based on physical activity or exercise (79% of respondents) or cognitive behaviour therapy (CBT) (55%) as a treatment or cure for M.E.

Their voices and experiences drove our consultation response to NICE to challenge areas of the draft guideline and endorse others.

We also:

- collaborated with other M.E. charities to respond quickly to the emerging data on Long Covid and reports of attempted treatment with graded exercise therapy and/or CBT
- facilitated hundreds of people with M.E. to have their say on a new position paper by the British Association for CFS/M.E., which set out how they will approach treatment and diagnosis.



We work alongside people with M.E. to highlight the significant and potentially lasting impact of the pandemic on their lives.

We worked with #MEAction UK and #MEAction Scotland to produce a survey to gather experiences from those living with M.E. who caught Covid-19. We will be using the results of this survey when lobbying for greater priority for people with M.E. when it comes to Government support and vaccines.



- **76%** of respondents said that Covid-19 made their M.E. symptoms worse.
- **72%** reported developing new symptoms, including shortness of breath, chest pain and dizziness.
- **70%** said this has lasted more than six months already and has still not resolved.

We responded to NICE's Rapid Response guideline on Long Covid setting out lessons that should be learnt from the experiences of people with M.E.

We used our position as a member of the South West Disability Unit to raise the experiences of people with M.E. during the pandemic with the Minister for Disabilities, Justin Tomlinson MP. We have also engaged with him on the upcoming Disability Strategy to express the importance of addressing the inequality experienced by disabled people.

We also:

- responded to two public House of Commons Select Committee enquiries calling for lessons to be learnt from the pandemic, highlighting the difficulties people experienced in securing food and the inequality experienced by people with a disability during the pandemic
- co-signed a letter with over 60 other charities to call on the Chancellor to extend the £20 Universal Credit uplift to legacy benefits
- helped organise virtual demonstrations to highlight the injustice experienced by people with M.E. on legacy benefits.

What next?

We will:

- work with the Long Covid Alliance to secure funding and policy changes
- increase the profile of M.E. with the World Health Organisation through the International Alliance for M.E.
- increase influencing activity at local and national level, focused on health, research and medical education.

By amplifying the voices and experiences of people with M.E., we increase awareness and reduce stigma.

Over the year, around 31.3 million people had the chance to see our interviews, letters and stories in newspapers and magazines, including online, highlighting the reality of life with M.E. The equivalent advertising value of this – what it would have cost us if we'd paid for similar coverage – was £1,019,110.

"Action for M.E has made me feel recognised and heard. The stories and research keep me optimistic and aware that I am not alone. I love the work they do."
Bethany (pictured), whose story we shared for M.E. Awareness Month



DecodeME was our biggest story of the year. The launch of the world's largest M.E. DNA study in June was covered in the mainstream and science press, alongside a carefully co-ordinated push on social media.



We empower people with M.E. to co-lead ground-breaking research

It was an exciting year for research with the announcement of funding from the Medical Research Council (MRC) and National Institute for Health Research (NIHR) for the world's largest DNA study, DecodeME.

We are co-leading the DecodeME partnership with Prof Chris Ponting (MRC Human Genetics Unit, University of Edinburgh) and a fantastic Public and Patient Involvement team. People with M.E. are at the heart of the project and involved in every aspect of its design and delivery.

£3.2m
funding for DecodeME

29,200 people receive regular updates (at time of writing)

91% (26,450) meet minimum requirements to get involved

Since the project started in September, we have been busy recruiting a team to work with us to take the study forward, communicating and engaging with the public and the M.E. community and securing ethical approval. We experienced some delays due to the pandemic and its impact on everything from contracts to securing cardboard boxes – one company bought them all at the beginning of the pandemic, causing a shortage!

By year end, more than 31,300 people were receiving regular updates. A majority of these meet the basic eligibility requirements of being 16 years or older and living in the UK with a diagnosis of M.E./CFS. So many people are keen to be involved, which is great, given that we need 20,000 people to take part and we know that not everyone will meet the strict research criteria to enable them to be involved.





We received £99,071 funding for a Priority Setting Partnership (PSP) to work collaboratively with people with M.E. and clinicians to identity the top 10 priorities for M.E. research.

"I am the mother and carer of my 22-year old daughter who has very severe M.E. I have years of experience of how the NHS treats people with M.E. – GP services, outpatients' clinics, inpatient services, clinical commissioning groups – as well as adult social care. I see this PSP as a key step forwards into a more positive future for everyone affected by M.E."
Rachel Elliot, PSP Steering Group

More than 1,560 responses, suggesting 2,000 research ideas, were shared with the PSP for its initial survey in July 2021. These are being sorted and collated before being shared in a second survey, which will ask the M.E. community to prioritise them.

This project, facilitated by non-profit making initiative, the James Lind Alliance, is funded by the NIHR, the Chief Scientist's Office, Scotland and the MRC. We will work with them to increase funding for research to address the priorities identified.

Our two funded PhD students completed their second year; both projects experienced delays as a result of the pandemic so will finish up to a year later than planned.



Joshua Dibble is working with Prof Chris Ponting comparing immune cells (T cells) from people with M.E. with those who don't.

Marissa Amato is based at the University of Sussex, working with Prof Neil Harrison, using imaging to better understand brain inflammation in people with M.E.

Our research strategy is to increase investment and interest in M.E. research. Both of our PhDs are match-funded: Joshua's by the Chief Scientist Office and Marissa's by the University of Sussex. This funding would not have been available without our investment. Additionally, we have attracted two fantastic scientists into the field.

"I would not be working in this field without the opportunity provided by this project. So even if you can only part-fund studentships (and find matching contributions) you will likely be able to draw new researchers to M.E./CFS research."
Joshua Dibble, PhD student we fund

Opportunities to stay in the M.E. field after completing a PhD are virtually non-existent, so we forged a partnership with US charity Solve M.E. to co-fund a trans-Atlantic fellowship. Profs Chris Ponting and Elizabeth Worthey (University of Birmingham, Alabama) will soon be recruiting a fellow who will benefit from working with two fantastic geneticists over a two-year period.

For every £1 we invest in fundraising, we raised more than 10 times that in donations.

Despite the challenges posed by the pandemic, this year our income exceeded £1 million and we ran our most successful Big Give Christmas Challenge ever.



£169,710 raised during Big Give



619 individual donations received



Our campaign ranked **5th** out of 764 charities taking part



£2,000 prize awarded by the Big Give for our campaign

In our five year strategy we committed to investing in the futures of children and young people with M.E. by increasing volunteer opportunities to develop new and existing skills.

We brought more volunteer peer-moderators into our young person's online forum. And with funding from Children in Need, we launched our three-year Breaking Isolation project in October aimed at decreasing isolation, increasing self-esteem and building positive relationships for young people with M.E.

This included establishing a steering group of five young people with M.E. to lead the design of the project and ensure it is accessible. One of the group co-facilitated the resulting workshops, too.

"Thank you so much for today's session, it helped me in so many ways and I've felt happier than I have in a long time."
Breaking Isolation workshop participant

What next?

We will:

- fund two PhD studentships with match-funding
- develop an evaluation framework to demonstrate impact of our research work
- co-fund a trans-Atlantic genetics fellowship
- ensure the voice and experiences of children and adults with M.E./CFS shape what we do and how we do it
- enhance our infrastructure
- invest in training and development to enhance skills, capability and leadership within our team
- increase the number of volunteers who work with us
- collaborate more with other M.E./CFS organisations.

Improving lives, inspiring action and investing in change: how can we do more and do better over the next five years?

Urgent action is needed to improve the lives of 250,000 children and adults with M.E. and their families also impacted by this disabling neurological illness.

M.E. has left hundreds of thousands of children and adults in the UK in lockdown for years, even decades. With quality of life worse than for those with congestive heart failure and other chronic diseases, and poor access to health, education and financial support available, it is sadly not surprising that the risk of suicide is six times higher than in the general population. Alongside the chronic, disabling symptoms of this neurological disease, people with M.E. tell us that isolation has a huge impact.

Over the past five years, we have taken action to end the ignorance, injustice and neglect experienced by over 250,000 children and young people in the UK – and there is still much more to do. We will keep working collaboratively with others to tackle the devastating issues experienced by people globally.

We will be announcing our transformative plans in autumn 2021. The following will give you a flavour of some of the discussions we have had as a team, with Trustees and partners, and colleagues in the M.E. community.

We will do more

We are a charity that punches above its weight but we do not have the level of resources to achieve the scale of change needed. We will need to be focused and determined in our new five-year plans. We have asked ourselves: what is important and urgent? What can create the level of transformation that is needed?

Research underpins knowledge and will lead to treatments. **Support services** improve people's health and wellbeing. **Medical education** reduces the stigma and disbelief people experience from professionals and ensures access to better support and care. These three universal areas affect everyone, and will be the focus of all our activities over the next five years.

Improving lives: health

Accessing key information, reassurance and useful resources, new users of our website increased by 60% from April 2016 to March 2021. Over the same period, we supported 43% more people by phone and email. We will continue to be here for those that need it most, and increase access for currently under-served communities, especially those from Black, Asian and other minority ethnic groups.

At the time of going to print, we are exploring a potential merger with the ME Trust. Both Action for M.E. and The ME Trust are frustrated by the considerable lack of provision for people with M.E. with a postcode lottery in access to specialist services and huge variability between them. There is simply not enough support for children and adults with M.E. now, let alone with an increase in diagnoses following Covid-19.

In response to this public health crisis and gaps in existing service provision for people with post-viral syndromes like M.E./CFS, a merger would allow us to combine the power of our organisations and strengthen the services we offer to people with M.E.

We will scale up the current clinician-led, holistic health and wellbeing support currently delivered by the ME Trust to fill the gaps more quickly.

"You are extremely helpful and skilled. Your assistance and ongoing direction and support mean the world to me."

July 2018 client, when we launched our pilot regional advocacy service

Investing in change: research

In 2016, we organised the third annual UK CFS/M.E. Research Collaborative (CMRC) conference, releasing the funding report showing that investment in M.E. research represents just 0.02% of all active grants given by UK mainstream funding agencies. The situation remains critical.

Transformation in research will not only lead to greater understanding and potential treatments but also directly challenge the stigma that still exists. We are exploring some exciting new developments and will share these later in 2021.

Alongside delivering the world's largest DNA study through DecodeME, we are working collaboratively to progress the priorities identified by people with M.E. and clinicians through the Priority Setting Partnership (PSP) that we are currently funded to deliver. We will continue to support the CMRC to secure increased funding for biomedical research while also seeking alternative ways to transform the research landscape. We will invest in bringing new researchers into the field through PhD studentships and Fellowships.

"What will I bring to the group? My personal experience of severe M.E., my connections to organisations and other individuals with M.E., a love of spreadsheets and data, and a drive to fight for high quality research that will create the meaningful change people with M.E. desperately need."

Sian Leary, PSP Steering Group

We will do better

What will support and services look for people with M.E. by the year 2027? The incoming NICE guideline, the potential merger between Action for M.E. and the ME Trust, and the investments being made in research offer us the opportunity to significantly influence this, led by people with M.E. in everything we do.

Over the next five years, it is our aim that our holistic services will facilitate improved access to health, support and advocacy services for children and adults with M.E., their families and those working with them, in a way we can measure and constantly strive to improve on. GPs will have increased understanding of M.E. and better recognise what helps and what harms their patients. There will be a roust research programme in place for one or more of the top ten priorities identified by people with M.E. through the PSP.

People with M.E. deserve better, and we will continue to work together with you and others who share our values and ambitions to achieve this.

Inspiring action: medical education

In October 2018, we worked with Forward-ME to co-host a busy exhibition stand and sold-out workshop on diagnosis, treatment and management at the Royal College of GPs' annual conference. Now we are delivering a range of medical education activities, working in collaboration with other charities and the Doctors with M.E. campaign group to promote Dr Nina Muirhead's highly rated learning module on M.E., and produce our Learn about M.E. podcast.

With expert input from our Medical Advisor, Dr David Strain (appointed July 2021), Senior Clinical Lecturer at the University of Exeter Medical School and Lead for the British Medical Association Covid-19 response team, we are exploring how to do more. When the 2021 NICE guideline is published, reflecting good-quality published evidence and patient experience, we will support its implementation as part of Forward-ME, the body which brings together most of the UK M.E. charities.

"The learning and literature was bang up to date and precisely the type of information doctors and other healthcare professionals need."

Joan Crawford, Counselling Psychologist

How we raised and spent our income this year

In our strategy, we promise to continue to strengthen our financial position and achieve the levels of income and efficiency we need to deliver the promises we make to people affected by M.E.

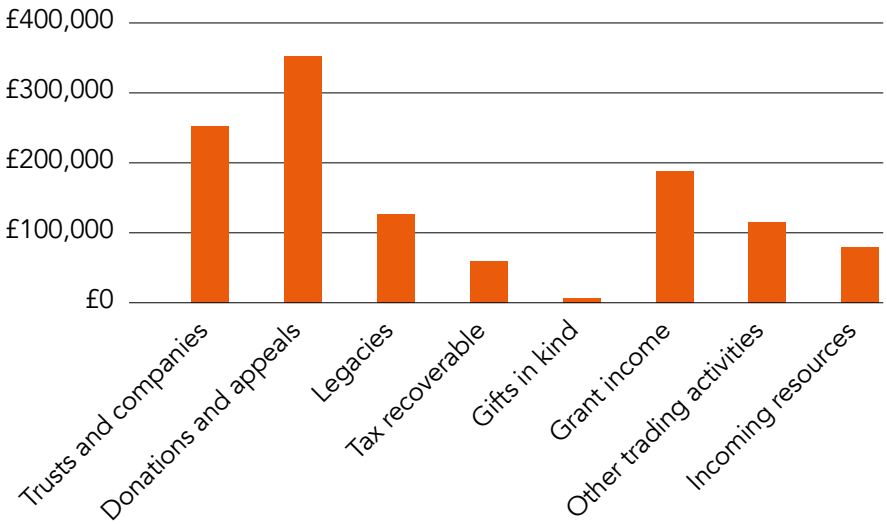
Our **recorded total income** (see bar chart below) for the year was £1,192,197, up 26% from the previous year. This is largely due to a record-breaking Christmas Big Give Challenge, increased success with trust applications and a number of legacies received during the year.

Overall expenditure was £832,594, a decrease of 16% from the previous year as a result of restructuring the charity in response to the Coronavirus pandemic and increased diligence in managing our resources during a time of such unprecedented global uncertainty. The net result is an overall surplus of £359,533. The charity ended the year with the equivalent of 16.6 months unrestricted operating costs in reserves. The Action for M.E. policy to is to hold four to six months of unrestricted operating costs. The additional reserves have been designated to invest in a transformative new strategy from 2022.



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

During 2020 – 2021, we raised £10.37 for every £1 invested in fundraising.



In our strategy, we promised to ensure that our organisation is as efficient and responsive as it can be.

This year we spent 60% of our income on charitable activities; including our one-to-one information and support services, peer support for adults and young people, our campaigning and influencing work, and our investment in collaborative biomedical research. This is down from 89% in the previous year. We reduced costs at the onset of the Covid-19 pandemic and then we were fortunate in ending the year with substantially higher income. So we were able to designate more than the additional income to spend on increasing services and research as part of our new strategic plan.

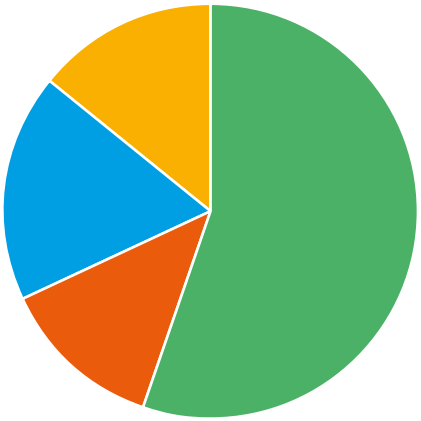
This year, we spent:

£462,196 on our information, advocacy and peer support services for adults, young people and families with M.E.

£106,296 on our campaigning and influencing work.

£148,293 on our investment in collaborative biomedical research.

£115,809 on fundraising (cost of generating voluntary income at £114,849, plus goods and trading at £960).



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 almost three quarters (73%) of our total gross expenditure is on staff salaries (including employer National Insurance and pension contributions).

Financial review

We remain the only M.E. charity in the UK providing support to both adults and children. As the likely impact of the Coronavirus pandemic became apparent at the start of financial year, the board of Trustees undertook a full budget re-forecast in April 2020 and significantly reduced the income forecast. This re-forecast was based on the vast majority of community fundraising events (walks, marathons and cycling) being cancelled and some trusts understandably re-focusing support to mitigate the effects of the pandemic. We also anticipated a significant drop in donations and membership subscriptions as many people were placed on furlough or reduced their individual giving. To ensure that we could continue to provide support to people with M.E. now and in the future, including handling a 30% rise in requests for support in April and May 2020, we restructured quickly from 1 April and reduced our staff team by 40% through furlough and not replacing vacant posts. In June 2020, we concluded a redundancy process that removed six permanent posts from the charity.

Thankfully, due to a phenomenal fundraising effort by our staff team and ongoing support from the M.E. community, we have seen our income increase by 26% compared to the previous year, achieving well over £1million in income together with a sound underlying financial performance, ending the year with a surplus of £359,533. We increased our digital fundraising activities and re-focused our trust fundraising work to make up for the predicted shortfall in community fundraising income. There are no contingent assets to report for the financial year 2020 – 2021. During the year the charity has been advised of a number of legacies and has received significant legacy income. 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.

This year's Big Give Christmas Challenge proved to be our most successful campaign ever, raising almost £170,000 to support our vital work to end the ignorance, injustice and neglect experienced by people with M.E. Our campaign was awarded second place in the Big Give awards and as a result we received an additional £2,000 towards our work.

Overall expenditure was £832,594, a decrease of 16% from 2019 – 2020. Between April and June 2020, as stated above we restructured as a result of the Covid-19 pandemic, reducing our staff team by 40%. The Board have approved increased investment in designated reserves to support our new strategy from 2022 and to ensure the charity retains a robust financial position given the ongoing uncertainties related to the pandemic. At year end, general funds were £268,050 (up £48,405). In addition the charity had designated funds of £340,000 (up £250,000). Restricted funds were £277,465 (up £61,128) which will be expended over the course of the next year on service delivery, biomedical PhDs and the Clare Francis Research Fellowship. 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.

We aim to raise £3 to £5 for every pound we spend on fundraising, to spend delivering our services and support. During 2020 – 2021, thanks to reduced costs, better-than-expected income and effective team working, we raised £10.37 for every £1 invested in fundraising (up from £6.91 last financial year).

Balance sheet

The surplus realised this year has increased our accumulated funds and cash reserves at the year end.

Funding sources

The principal funding sources for Action for M.E. are charitable trusts, legacy giving, community fundraising and events, Supporting Membership income, and individual gifts. Other funding sources include Gift Aid, Christmas card sales, raffles and other trading.

Despite having a diverse and broad funding base, we anticipate a challenging year of fundraising in 2021 – 2022 as the full economic impact of Covid-19 is felt across the sector and beyond. This year, we are enormously grateful for support from The Masonic Charitable Foundation, Scottish Government, John Swire (1989) Charitable Trust, Philip King Charitable Trust, the De Laszlo Foundation, the Garfield Weston Foundation, Sir James Reckitt Charity, The James Tudor Foundation, The Robert McAlpine Foundation and Eveson Charitable Trust.

The Bank of Scotland Foundation generously supported our Crisis, Support and Advocacy service in Scotland.

Funding from the Coronavirus Community Support Fund, distributed by The National Lottery Community Fund, helped us to provide support to people with M.E. throughout the UK in desperate need through the pandemic. Thank you to the Government for making this possible.

HM Government

In partnership with

THE NATIONAL LOTTERY COMMUNITY FUND

We also thank Pears Foundation for funding the extension of our advocacy service as part of the Government's £750m charities package, granted through Pears Foundation's trusted, long-term partners to ensure funding gets to frontline organisations and their communities.

Pears Foundation

Financial review

Investment policy

Aside from retaining a prudent amount in reserves each year, most of the charity's funds are spent in the short term so there are few funds for long-term investment. During the financial year 2020 – 21, given the significant designated reserves position the charity invested £50,000 in the M&G Charibond fund following a process of due diligence. The charity has an investment policy which currently uses the COIF Charities Investment Fund to provide a short term interest-bearing account that optimises the balance between flexibility and rate of return, and is exploring ways of improving the return on its cash resources.

Reserves policy

The current policy is to maintain the level of 'free' (unrestricted) funds at no less than four times, and no more than six times, the monthly unrestricted running costs of the charity. Previously, our policy was to hold three to five months of unrestricted reserves but this was increased in February 2021 in light of the economic uncertainty related to the pandemic. The charity ended the financial year with 7.3 months of unrestricted reserves based on an unrestricted monthly expenditure of £36,657.

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 statements 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.

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 judgments and accounting estimates that are reasonable and prudent
- prepare the financial statements on the 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 time, the financial position of the charity and enable them to ensure that the 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 (previously known as Moore–Stephens) was re-appointed as our auditor at the 2020 Annual General Meeting.

Provision of information to Auditor

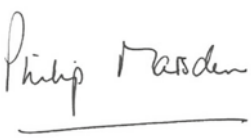
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish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



Roger Siddle
Chair of Board of Trustees
and Directors



Philip Marsden
Director and Treasurer

Approved by the Board of Trustees
and signed on its behalf on
31 August 2021

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 to 14.

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, to give strategic direction, and to 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 Officer.

Day-to-day operations are overseen by the Operations Director, whose quarterly reports to the Board include a report against key performance indicators identified in our high level delivery plan.

Our committees

Four 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 Committee meets quarterly and reviews finances, risk controls, audit requirements, fundraising, and income generation activity to support and grow our work.

- The Policy Group meets quarterly and provides a steer for the charity's policy and influencing work at local, national and international level

.

- The Research Panel meets twice a year and monitors the charity's research-funded activity.

- The Remuneration and Nominations Committee meets as and when required, to make recommendations to the Board on senior appointments and related significant employment contract issues.

All staff members, including the Chief Executive, have performance targets 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 October 2020). 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 education professionals, government and senior officials, and other decision-makers. As a member of a number of organisations and alliances, including Forward M.E., Advice Centres for Avon, 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.

Our people, structure and governance

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 (see p10).

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 35. 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 (eg. 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 always be protected, and the trust of our supporters must not be violated. The policy also sets out the way in which we deal with fundraising complaints.

Risk

The Operations Director 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 to protect the quality of our work, reputation and income.

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.

To ensure good governance in light of our projected drop in income as a result of Covid-19, we made a serious incident report to the Charity Commission on 23 March 2020 (the date was mistakenly given as April 2020 in last year's report). While we took immediate action to record this incident, the Commission later decided charities were not required to refer incidents such as this if related to the pandemic. As serious incident reports are not deleted, ours stands despite this change from the Commission.



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 2021 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 2021 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 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 Trustees' responsibilities Statement set out on page 16 , 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 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.

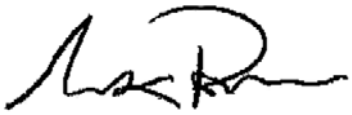
- Evaluate the overall presentation, structure and content of the financial statements, including the disclosures, and whether the financial statements represent the underlying transactions and events in a manner that achieves fair presentation.

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
24 September 2021

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2021

	Notes	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	621,035	378,071	999,106	828,678
Other trading activities	3	35,557	75,763	111,320	34,775
Investment income	4	301	–	301	1,268
Incoming resources from charitable activities	3	81,400	–	81,400	84,806
Total incoming resources		**738,293**	**453,834**	**1,192,127**	**949,527**
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	108,849	6,000	114,849	137,470
Fundraising trading: costs of goods sold and other costs		946	14	960	3,521
Charitable activities	5	330,093	386,692	716,785	844,986
Total resources expended		**439,888**	**392,706**	**832,594**	**985,977**
Net movement in funds	12	298,405	61,128	359,533	(36,450)
Reconciliation of funds					
Fund balances at 1 April 2020		309,645	216,337	525,982	562,432
Fund balances at 1 April 2021		**608,050**	**277,465**	**885,515**	**525,982**

All incoming resources and resources expended derive from continuing operations. The notes on p 25 to 35 form an integral part of these accounts.

Balance sheet

As at 31 March 2021 (company registered number 2906840)

	Notes	2021 (£)	2020 (£)
Fixed assets			
Tangible assets	9	27,679	27,181
Investments	10	50,000	–
Total fixed assets		**77,679**	**27,181**
Net current assets			
Debtors	11	192,832	130,037
Cash at bank and in hand		689,256	421,808
Total current assets		882,088	551,845
Creditors: Amounts falling due within one year	12	(74,252)	(53,044)
Net current assets		807,836	498,801
Total assets less current liabilities		**885,515**	**525,982**
Capital and reserves			
General funds		268,050	219,645
Designated funds	13	340,000	90,000
Unrestricted funds		608,050	309,645
Restricted funds	14	277,465	216,337
Accumulated funds		**885,515**	**525,982**

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 24 to 34 form an integral part of these accounts.

Roger Siddle
Chair of Board of Trustees and Directors

Philip Marsden
Treasurer

Approved by the Board of Trustees 31 August 2021

Action for M.E. cash flow statement for the year ended 31 March 2021

		2021	2020
Net cash flow from operating activities	See note a below	329,269	(143,610)
Net cash flow from investing activities	See note b below	(61,821)	(8,971)
Net increase in cash and cash equivalents		267,448	(152,581)
Cash and cash equivalents at beginning of period		421,808	574,389
Cash and cash equivalents at end of period		689,256	421,808

Notes to the cash flow statement

a Cash flows from operating activities

	£	£
Net movement in funds	359,533	(36,450)
Depreciation	11,624	8,649
Financial income	(301)	(1,268)
	370,856	(29,069)
(Increase)/decrease in debtors	(62,795)	(43,655)
(Decrease)/increase in creditors	21,208	(70,886)
NET CASH FROM OPERATING ACTIVITIES	329,269	(143,610)

b Cash flows from investing activities

	£	£
Purchase of tangible fixed assets	(12,122)	(10,239)
Interest received	301	1,268
Investment in financial assets	(50,000)	–
NET CASH FROM INVESTING ACTIVITIES	(61,821)	(8,971)

Analysis of changes in Net Funds

	At 01.04.2020 (£)	Cash Flow (£)	At 31.03.21 (£)
Cash at Bank	421,808	267,447	689,256
Total	**421,808**	**267,447**	**689,256**

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 34. 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 no 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.

Fund accounting

General funds are unrestricted funds which are available for use at the discretion of the Trustees in furtherance of the general objectives of the Charity and which have not been designated for other purposes. Designated funds comprise unrestricted funds that have been set aside by the Trustees for particular purposes. The aim and use of each designated fund is set out in the notes to the accounts. Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the Charity for particular purposes. The aim and use of each restricted fund is set out in the notes to the accounts.

Deferred Income

In accordance with the FRS 102 SORP issued by the Charity Commission for England and Wales and the Office of the Scottish Charity Regulator, grants received in advance and specified by the donor as being subject to specific terms and conditions are deferred until the conditions applying to the grant are within the control of the Charity and it is probable that the imposed terms and conditions can be met. Such deferrals are shown in the notes to the accounts and the sums involved are shown as creditors in the accounts.

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 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 or 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 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 in order to write off the cost of the assets (less their expected residual value) over their estimated useful economic lives. Office Equipment – 25% on 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 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 £18,566 (£24,008 in 2020).

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.
- A Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy for small projects has an agreed 'in kind value' of £1,000.
- A further gift in kind value of £900 has been recorded for podcast work undertaken for a project in Scotland and an amount of £1,300 towards other legal services.
- 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 (£)	**Restricted funds (£)**	**Total 2021 (£)**	Total 2020 (£)
Donations and legacies				
Trusts and companies	104,406	149,422	**253,828**	263,261
Donations and appeals	326,027	27,395	**353,422**	317,675
Legacies	114,042	13,882	**127,924**	130,995
Tax recoverable	63,360	4,039	**67,399**	57,551
Gifts in kind	3,200	–	**3,200**	5,493
Grant Income	10,000	183,333	**193,333**	63,703
	621,035	**378,071**	**999,106**	828,678
Other trading activities				
Lotteries and raffles	11,889	–	**11,889**	9,743
Christmas cards	2,602	–	**2,602**	3,653
Supplement commission	2,588	–	**2,588**	1,688
Merchandise	163	141	**304**	965
Events	–	–	**–**	750
Other	18,315	75,622	**93,937**	17,976
	35,557	**75,763**	**111,320**	34,775
Incoming resources from charitable activities				
Subscriptions	81,377	–	**81,377**	82,906
Charity journal	–	–	**–**	1,568
Information and publications	23	–	**23**	332
	81,400	**–**	**81,400**	84,806

Details of 2020 income	Unrestricted funds (£)	Restricted funds (£)	Total 2020 (£)
Donations and legacies			
Trusts and companies	90,348	162,913	253,261
Donations and appeals	282,128	35,547	317,675
Legacies	130,995	–	130,995
Tax recoverable	53,291	4,260	57,551
Gifts in kind	2,000	3,493	5,493
Grant Income	–	63,703	63,703
	558,762	**269,916**	**828,678**
Other trading activities			
Lotteries and raffles	9,743	–	9,743
Christmas cards	3,653	–	3,653
Supplement commission	1,688	–	1,688
Merchandise	368	597	965
Events	750	–	750
Other	16,823	1,153	17,976
	33,025	**1,750**	**34,775**
Incoming resources from charitable activities			
Supporting Membership	82,906	–	82,906
Membership magazine	1,568	–	1,568
Information and publications	332	–	332
	84,806	**–**	**84,806**

4 Investment income

	2021 (£)	2020 (£)
Interest from cash investments in the UK	**301**	**1,268**
	301	**1,268**

5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Costs of generating voluntary income				
Staff costs	13,965	–	**13,965**	28,420
Direct fundraising costs	11,102	–	**11,102**	13,968
Support costs – see below	83,782	6,000	**89,782**	95,082
	108,849	**6,000**	**114,849**	**137,470**

	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Charitable activities				
Information and support services	193,908	268,288	**462,196**	489,961
Campaigning and influencing work	103,329	2,967	**106,296**	289,795
Collaborative biomedical research	32,856	115,437	**148,293**	65,230
	330,093	**386,692**	**716,785**	**844,986**

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

	Activities undertaken directly	Support costs as below	Total (£)
Activity			
Information and support services	87,126	106,782	**193,908**
Campaigning and influencing work	70,473	32,856	**103,329**
Collaborative biomedical research	–	32,856	**31,856**
	157,599	**172,494**	**330,093**

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 £
Support costs						
Communications and policy	3,929	4,443	3,338	17,902	3,244	**32,856**
Information and services	12,769	14,440	10,849	58,182	10,542	**106,782**
Research	3,929	4,443	3,338	17,902	3,244	**32,856**
	20,627	23,326	17,525	93,986	17,030	**172,494**
Fundraising	10,019	11,330	8,512	45,650	8,271	**83,782**
	30,646	**34,656**	**26,037**	**139,636**	**25,301**	**256,276**

Office costs include £3,200 (£2,000 in 2020) for professional services in kind.

	2021 (£)	2020 (£)
Governance costs		
Administrative salaries – based on time spent	**22,400**	13,641
Indemnity insurance for Trustees	**1,774**	2,314
Governance training and travel	**1,320**	2,674
Trustees' expenses	**–**	3,275
Meeting room hire and refreshment costs	**–**	5,268
Auditors' fees	**6,400**	6,250
Professional fees	**604**	400
Design and printing	**756**	1,312
Postage and office supplies	**32**	**168**
	30,646	35,302

	2021 (£)	2020 (£)
Grant activities		
The University of Sussex – PHD in biomedical research	15,664	15,243
The University of Edinburgh – PHD in biomedical research	–	2,306
	15,664	17,549

Details of 2020 expenditure	Unrestricted funds (£)	Restricted funds (£)	2020 (£)
Costs of generating voluntary income			
Staff costs	28,420	–	**28,420**
Direct fundraising costs	10,934	3,034	**13,968**
Support costs – see below	95,082	–	**95,082**
	134,436	**3,034**	**137,470**
Charitable activities			
Information and support services	303,597	186,364	489,961
Campaigning and influencing work	279,086	10,709	289,795
Collaborative biomedical research	11,319	53,911	65,230
	594,002	**250,984**	**844,986**

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

	Activities undertaken directly	Support costs as below	Total (£)
Activity			
Information and support services	115,696	187,901	**303,597**
Campaigning and influencing work	193,059	86,027	**279,086**
Collaborative biomedical research	–	11,319	**11,319**
	308,755	**285,247**	**594,002**

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 £
Support costs						
Communications and policy	7,985	12,127	7,553	50,540	7,822	**86,027**
Information and services	17,441	26,488	16,498	110,390	17,084	**187,901**
Research	1,051	1,595	994	6,650	1,029	**11,319**
	26,477	40,210	25,045	167,580	25,935	**285,247**
Fundraising	8,825	13,403	8,349	55,860	8,645	**95,082**
	35,302	**53,613**	**33,394**	**223,440**	**34,580**	**380,329**

6 Net movement in funds

	2021 (£)	2020 (£)
This is stated after charging:		
Operating lease	**18,430**	27,311
Depreciation of owned fixed assets	**11,605**	8,649
Auditor remuneration	**6,400**	6,250
Trustees' expenses	**–**	3,275
Pension costs	**36,435**	20,121

Funds belonging to the Charity have been used for the purchase of insurance to protect the Charity from loss arising from the neglect or defaults of its employees or agents, acting as such, or to indemnify the employees, acting as such, against the consequences of any neglect or default on their part.

This does not cover any employees who are also Trustees in their capacity as Trustees and acting as such. The sum expended by the Charity on such insurance for the year to 31 March 2021 was £1,774 (in 2020 it was £2,322).

7 Staff costs and emoluments

	2021 (£)	2020 (£)
Gross salaries	**543,595**	585,545
Employer's National Insurance	**45,857**	51,107
Pension contributions	**18,440**	20,121
	607,892	656,773

Numbers of full-time employees or full-time equivalents		
	2021	2020
Engaged on charitable activities	**11**	13
Engaged in fundraising activities	**4**	4
Engaged on management and administration	**4**	4
	19	**21**

The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:	**Number**	Number
	1	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 £87,391 (£87,391 in 2020).

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

	2021 (£)	2020 (£)
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 five Trustees for travel and accommodation for the purpose of attending Board meetings.	–	3,275
Amounts of expenses incurred by Trustees that were donated back to the Charity.	–	406
There were no related party transactions up to 31 March 2020.		

9 Tangible fixed assets

	Office equipment (£)
Cost	
At 1 April 2020	54,775
Additions for year	12,122
Disposals in year	–
At 31 March 2021	**66,897**
Depreciation	
At 1 April 2020	27,594
Charge for year	11,624
Disposals in year	–
At 31 March 2021	**39,218**
Net book value	
At 31 March 2020	27,181
At 31 March 2021	**27,679**

10 Investments

Market value	
At 1 April 2020	50,000
Revaluations	–
At 31 March 2021	50,000
Net book value	
At 31 March 2020	–
At 31 March 2021	**50,000**

There were no investment assets outside of the UK.

11 Debtors

	2021 (£)	2020 (£)
Trade debtors	**41,397**	120
Prepaid expenses	**28,911**	24,849
Due from HMRC	**–**	2,920
Accrued income	**122,524**	102,148
	192,832	130,037

12 Creditors: amounts falling due within one year

	2021 (£)	2020 (£)
Trade creditors	**43,054**	18,247
Deferred income	**–**	721
Accrued expenses	**15,178**	17,746
Unpaid pension contributions	**3,482**	3,451
Due to HMRC	**897**	–
Other taxation and social security costs	**11,641**	12,879
	74,252	53,044

13 Funds

	General funds (£)	Designated funds (£)	Total (£)
Statement of unrestricted funds			
Balance at 1 April 2020	219,645	90,000	**309,645**
Transfer between funds	(250,000)	250,000	**–**
Surplus for year	298,405	–	**298,405**
Balance at 31 March 2021	**268,050**	**340,000**	**608,050**

	Tangible fixed assets (£)	Cash	Other Net current assets (£)	Total (£)
Analysis of net assets between funds – current year				
Unrestricted funds:				
General funds	27,679	137,344	103,027	**268,050**
Designated funds	–	340,000	–	**340,000**
	27,679	477,344	103,027	**608,050**
Restricted funds	–	211,911	65,554	**277,465**
	27,679	689,255	168,581	**885,515**

	Tangible fixed assets (£)	Cash	Other Net current liabilities (£)	Total (£)
Analysis of net assets between funds – prior year				
Unrestricted funds:				
General funds	27,181	115,471	76,993	**219,645**
Designated funds	–	90,000	–	**90,000**
	27,181	205,471	76,993	**309,645**
Restricted funds	–	216,337	–	**216,337**
	27,181	421,808	76,993	**525,982**

14 Restricted funds

	Opening balances £	Incoming resources £	Outgoing resources £	Closing Balances £
Movements in restricted funds				
Research	125,084	57,879	35,217	**147,746**
Priority Setting Partnership	–	99,072	33,518	**65,554**
DecodeME	–	46,702	46,702	**–**
Crisis, Support and Advocacy	44,272	137,478	127,291	**54,459**
Mentor M.E.	42,103	63,703	105,806	**–**
M.E. Friends Online	–	10,000	5,172	**4,828**
Printed resources	4,878	–	–	**4,878**
Government furlough grant	–	23,920	23,920	**–**
Operations	–	15,080	15,080	**–**
	216,337	**453,834**	**392,706**	**277,465**

Research – donations received from donors wishing to see advances in research. Two co-funded PhD students have been supported in part from this fund during the year. See the grant activities table on p 28 for more details.

Priority Setting Partnership – funding to manage and administrate this project led by people with M.E., carers and clinicians, and facilitated by the James Lind Alliance, which aims to influence future M.E. research funding.

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.

Crisis Support and Advocacy – donations for our support services, combined into a UK-wide service for people with M.E. of all ages, in response to the Covid-19 pandemic.

Mentor M.E. – funded by Health and Social Care Alliance Scotland from the Transforming Self-Management in Scotland Fund. This project developed a network of volunteer peer mentors supporting people living with M.E. in Scotland, ending in March 2021.

M.E. Friends Online – our forum for adults with M.E. to share peer-support, friendship and practical tips about living with M.E.

Printed resources – Grant for revising three of our key printed publications: All about M.E., Your child and M.E. (for parents) and Caring for someone with M.E. (for carers).

Government Furlough Grant – Government funding for the wages of the staff members we put on furlough because of Covid-19.

Operations – funding towards operational programme design and delivery, driving positive change and improvement and developing powerful impact measures.

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 £3,482 (£3,451 in 2020) 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 2021 (£)	Total Leases 2020 (£)
Operating lease payments falling due:		
within one year	30,895	26,917
within two to five years	122,440	1,710
over five years	53,070	–
	206,405	**28,627**

17 Contingent assets

During the year the Charity has been advised of a number of legacies and has received significant income. 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 £105,000 of which £75,000 is to be spent in the year to 31 March 2022.

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

Trustees and Directors 2020 – 2021

President

Clare Francis MBE

Founding President

Sue Finlay

Vice President

Martin Arber

Patrons

Lord Bragg
Julie Christie
Lord Puttnam CBE
Alan Cook CBE
Prof Anthony J Pinching

Honorary Patron

Ondine Upton

Board of Trustees

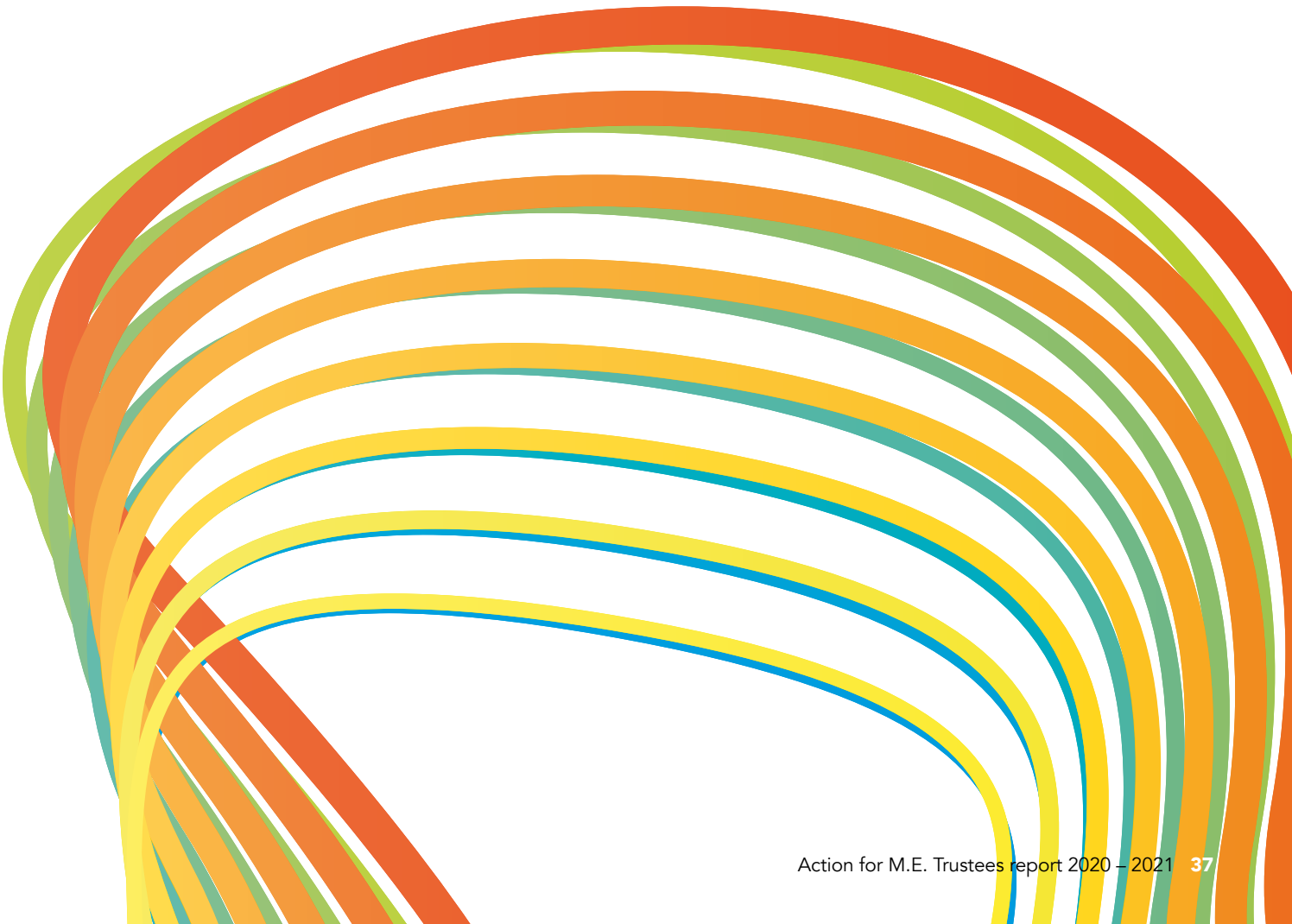
Roger Siddle, Chair
Philip Marsden, Treasurer
Matt Symonds
Colin Batten
Christopher Cundy
(stood down October 2020)
Shaun De Boo
(joined February 2021)
Alison Deeth
Andy Dougan
(stood down October 2020)
Lucy Goodwill
Sue Hardy
David Leigh
(joined December 2020)
Jonathan Manuel
(joined March 2021)
Phil Murray
Jane Stacey
Ed Stephens
Jane Young
(stood down October 2020)

Chief Executive

Sonya Chowdhury

Principal Medical Advisers

Dr Gregor Purdie
Prof Julia Newton



"Myself and my daughter have been members of the charity following my daughter's diagnosis of M.E. in 2015. We have had lengthy battles with various organisations who do not seem to acknowledge M.E. and the difficulties and restrictions it can present. Throughout our battles we have found advice, support and information from Action for M.E. to always prevail and I really do not know where we would be if this charity did not exist. You have literally been a life saver and allowed us to keep our sanity. We are both so grateful and felt it was the least we could do to make contact and pass on our gratitude. We will continue to support you and cannot thank you enough."

Action for M.E. supporter



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Keynsham
BS31 1EH
Crisis, Advocacy and Support Service: 0117 927 9551
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Registered in Scotland no. SC040452
Company limited by guarantee, registered in England no. 2906840
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