



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 regrettably 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."



"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.

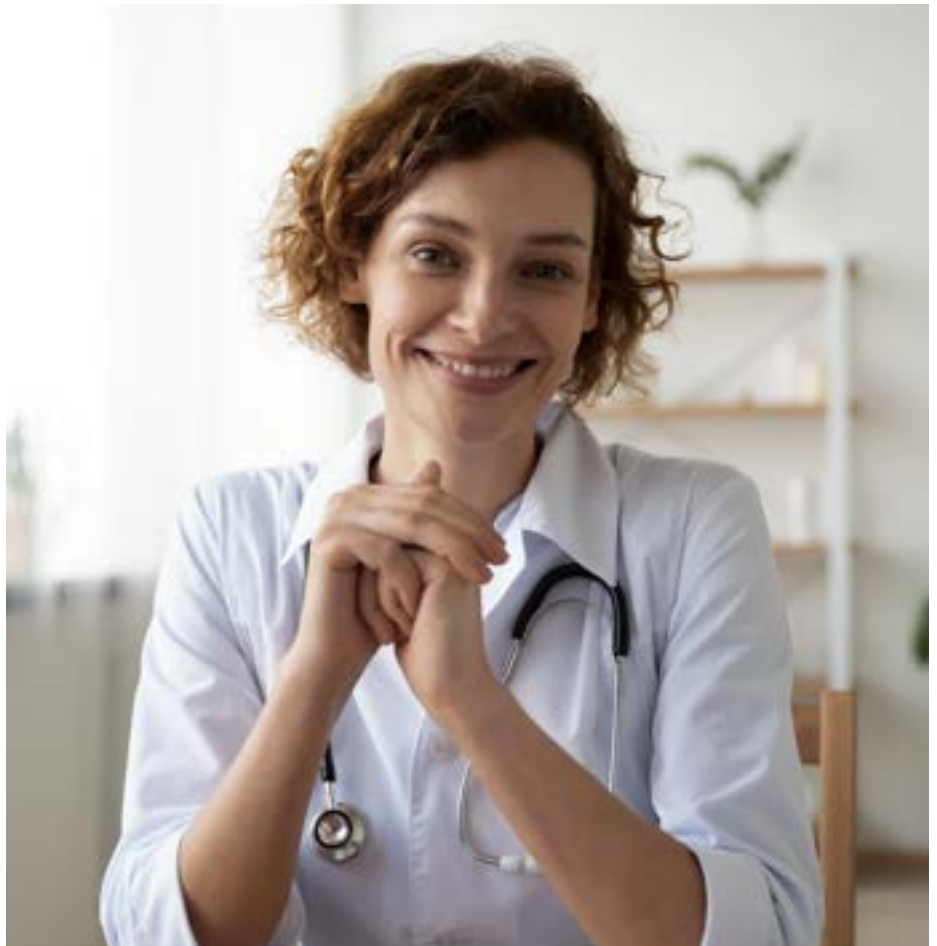
Over 40% of these individuals received bursary support from Action for M.E., ensuring that financial barriers did not prevent access to the care they needed.

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.

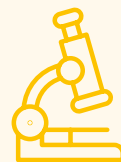
We were pleased to work with DecodeME colleagues and a number of mainstream news outlets to amplify the important findings and generate further awareness of the groundbreaking study.



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.

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



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



Fleur Anderson MP

Carol Monaghan MP

Debbie Abrahams MP

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.

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 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



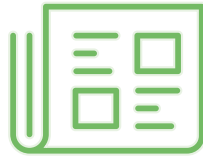
85%
of children and young people said they feel less isolated after accessing our Children and Young People's Community



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



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

"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:

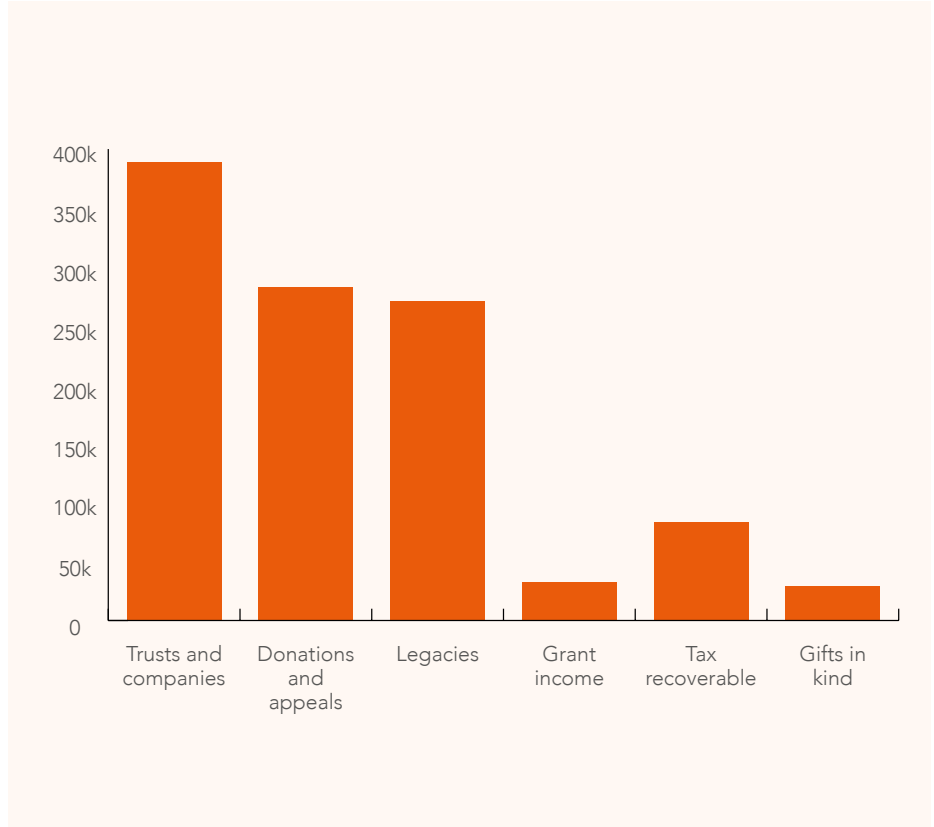
Anna Leaf Foundation
 One Gloucestershire Integrated Care System
 Christopher Laing Foundation
 Doris Field Charitable Trust
 Eveson Charitable Trust
 Gerald Bentall Trust
 Hugh Fraser Foundation
 Johnsons Group Cleaners Charity
 National Lottery Reaching Communities
 One Gloucestershire Integrated Care 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.

£194k

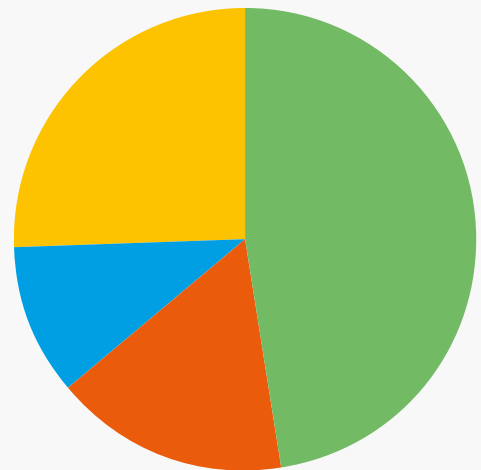
on our investment in collaborative biomedical research.

£445k

on fundraising.

£295k

on our campaigning and influencing work.



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.

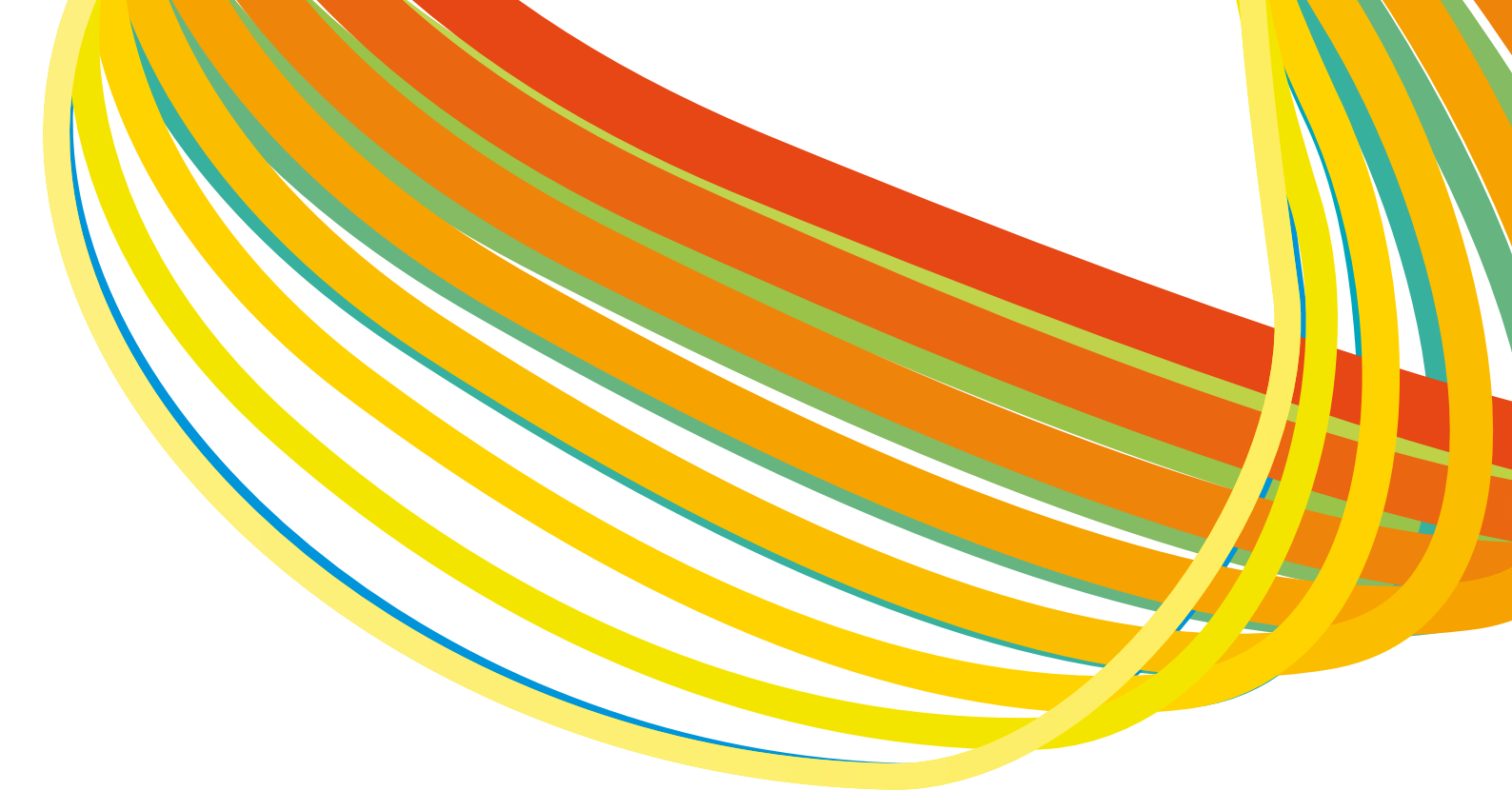
Supporting Members vote on new appointments and the re-election of existing Trustees, with results subsequently confirmed at our Annual General Meeting) held this year in September 2024. Each new Trustee receives a full induction and has the opportunity to be paired with a 'buddy' for the first year 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 Siddie
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 | | <u>(211)</u> | <u>235</u> |
| Cash and cash equivalents at beginning of period | | 1,277 | 1,043 |
| Cash and cash equivalents at end of period | | <u>1,066</u> | <u>1,277</u> |

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) |
| | | <u>(69)</u> | <u>(665)</u> |
| (Increase)/decrease in debtors | | (151) | 908 |
| a (Decrease)/increase in creditors | | (15) | (10) |
| b Net cash from operating activities | | <u>(235)</u> | <u>233</u> |

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 | | <u>24</u> | <u>2</u> |
| | 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 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 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 |
| Average number of employees | 2024 | 2023 |
| 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 resources (£'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 by 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 charity 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

Trustees and Directors 2023 – 2024

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 Advisor

Denise McLellan

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Roger Siddle, Chair
Jonathan Manuel, Treasurer
Colin Batten
Philip Courtney
Shaun De Boo
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

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

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Registered in Scotland no. SC040452
Company limited by guarantee, registered in England no. 2906840
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