

Action for M.E. Trustees' report

2021 – 2022



We need quality research to create
meaningful change.



The Top 10+ ME/CFS Research Priorities
Visit www.psp-me.co.uk

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 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

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.



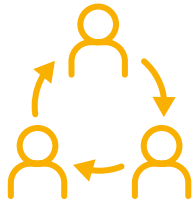
Roger Siddle
Chair of Board of Trustees
Action for M.E.

"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."



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."



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.



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."

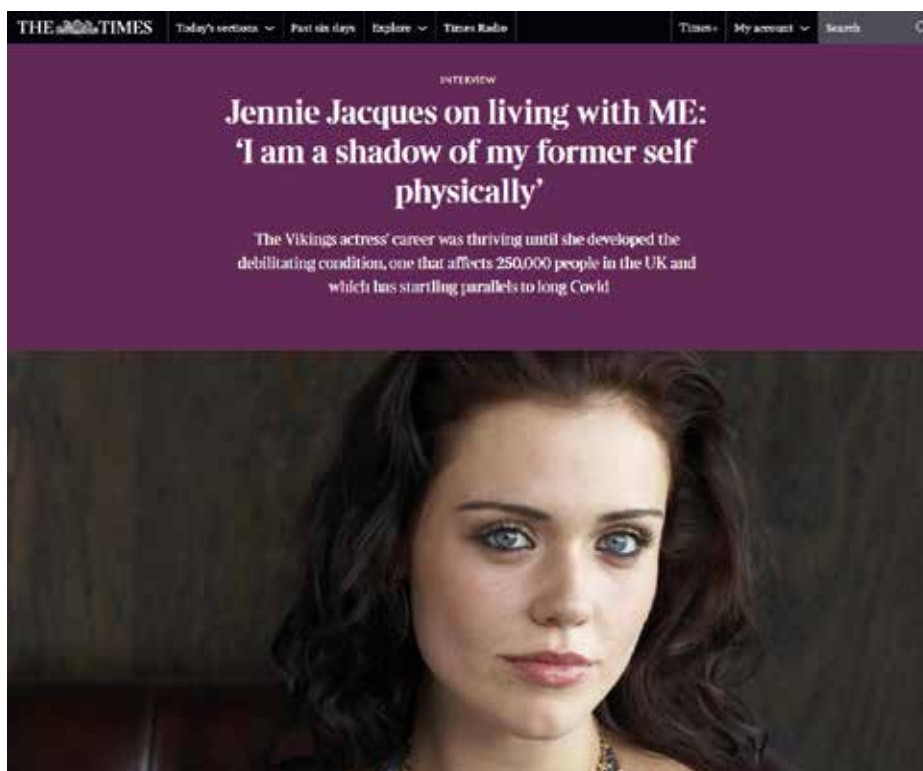
Dr Shaun Peter Qureshi

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



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



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 charity 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 be 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.

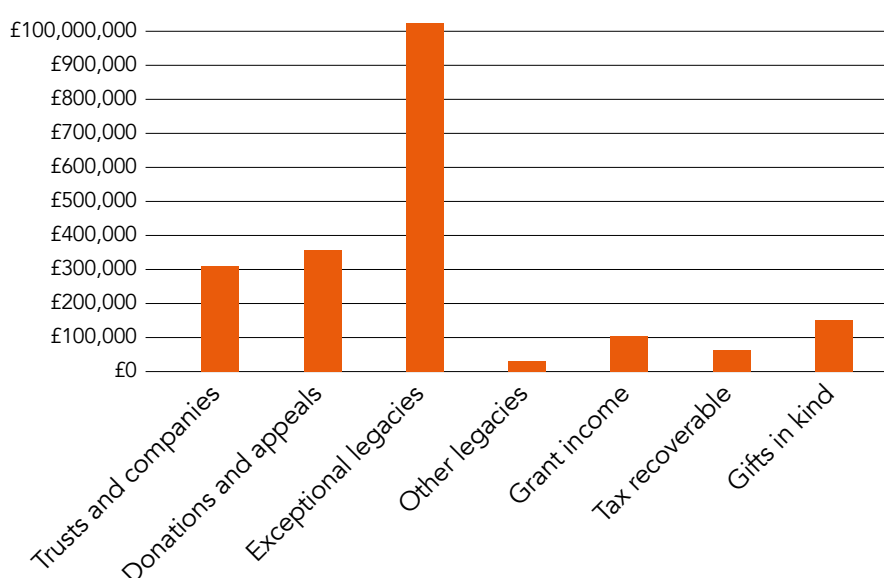
Overall expenditure was £1.3million, an increase of 59% from the previous year as a result of increased expenditure on frontline services, designation for increased collaborative biomedical research activity, and planned increases to the staff team to put the charity in a strong position to deliver our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

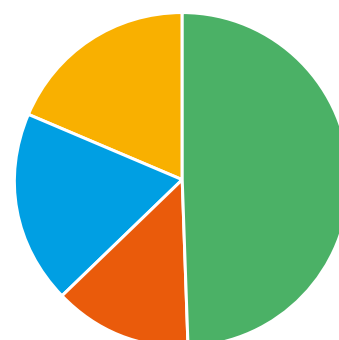
In our statement of strategic intent, we promised to improve healthcare and information for people with M.E.

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 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 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.

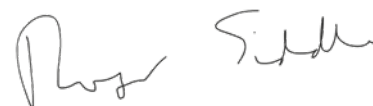
Provision of information to Auditor

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.

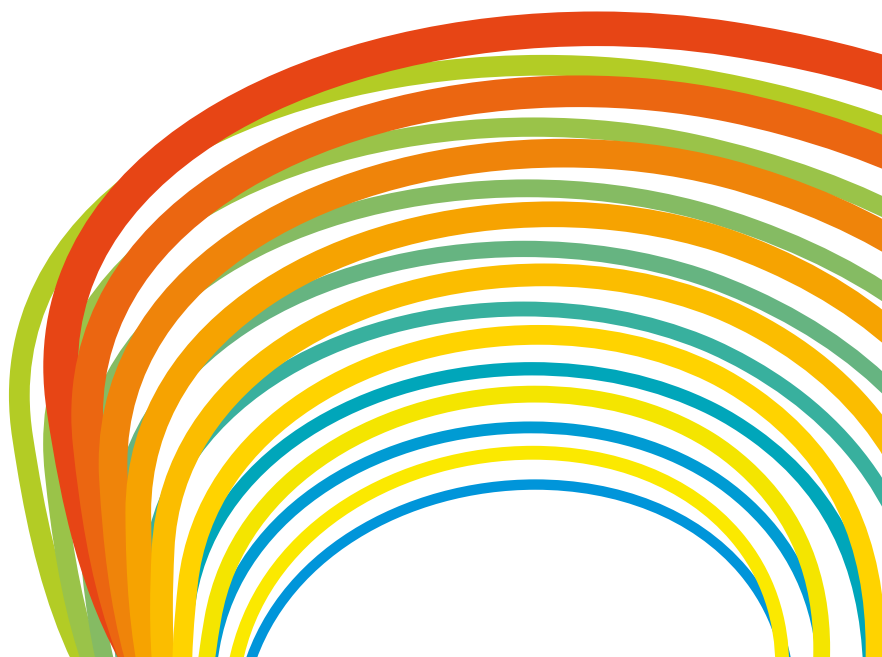


Roger Siddle
Chair of Board of Trustees and Directors



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.

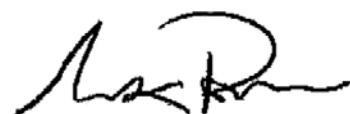
We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

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

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

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

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

There were no related party transactions up to 31 March 2022.

2022 (£)	2021 (£)
–	–
476	–
280	–

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

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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



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