



Action for M.E. Trustees' report

2019 – 2020



Improving access to education

"It's an amazing feeling knowing somebody totally understands our situation."

Being there to improve lives, like Lloyd's

Adapting quickly to save our vital services...

While it is hard to look ahead with any certainty given the pandemic, we do know that now, more than ever, people with M.E. are at risk of increased isolation and lack of support. We remain the only M.E. charity in the UK providing support to people with M.E. of all ages. We are ambitious for change and will take action to achieve it.

We have many exciting plans and opportunities. After three months of lockdown, in the face of a global pandemic, we were hugely excited to announce the launch of DecodeME, the world's largest DNA M.E. study. Securing £3.2m funding for this ground-breaking research has been the culmination of years of hard work and collaboration between people with M.E., scientists, advocates and Action for M.E.

Work formally starts on the £3.2m DecodeME project in Autumn 2020. We have a mammoth job ahead in working with our M.E./CFS Biomedical Partnership colleagues to set up this research, secure the necessary ethical approval, and recruit 20,000 people with M.E. before the genetic analysis begins. By working together, we are confident we will deliver.

Alongside this, we are working with a Steering Group of people with M.E. and clinicians to set up the Priority Setting Partnership to identify the top 10 clinical research priorities for M.E. This work, funded by the National Institute of Health Research, the Scottish Government Chief Scientist Office and the Medical Research Council, will help set strategic goals for future clinical research funding based on the voices of people with M.E. We will continue to work collaboratively with forums such as Forward M.E. to influence policy and decision-makers and enhance medical education.

We've almost reached the end of our five-year strategy and we have delivered our promises to improve lives, inspire action and invest in change. We are using our Big Survey results from over 4,000 people with M.E., and consultation with others, to inform our goals and objectives for the next five years. We have seen a sustained 30% increase in demand for services since the lockdown. We adapted quickly with a reorganisation to ensure we are there when we are needed the most, offering expanded services across the UK to children and adults with M.E. and their families and professionals working with them.

Additionally, we know that there is a disproportionate gap in service provision for people from Black, Asian and other minority ethnic groups. With the likelihood of an increase in the number of people being diagnosed with M.E. following post-viral Covid-19, this gap may well get bigger.

We have worked to make our services more accessible but we have so much more we can, and must, do. Black Lives Matter has helped many of us refocus on addressing racial and cultural disadvantage. We will step up and take personal and organisational responsibility for taking stronger action.

We value the support of our friends and donors and cannot achieve our ambitions without you. I am often asked "What more can I do?" so here are three things that would ensure we continue to improve lives now and in the future:

- Providing services and lobbying for change cannot be done without funds. Donations, fundraising and other support that enables us to increase our networks of potential donors is critical.

- Money is essential – but so is amplifying our voice. Sharing our content online, writing to your MPs or local media, or talking to other people about M.E. and its impact, all help shine a light on the needs of people with M.E.
- Recruiting 20,000 people aged over 16 in the UK with M.E., who meet the strict research criteria for DecodeME is going to be a challenge. Supporting recruitment to help us reach this goal quickly means we can move one step closer to understanding more about the illness. Our aim is to enable development of targeted treatments and one day find a cure, so our vision of a world without M.E. becomes a reality.

We do not know what the future holds but we are committed, as always, to working collaboratively, effectively and with determination to ensure that we are here when people need us.



Sonya Chowdhury
Chief Executive
Action for M.E.



...and making every bit of support count.

Being there to support children and adults with M.E when they need us most has always been our top priority but few could have predicted what 2020 would bring.

During the year just passed, we worked with more people than in previous years through our information and support services. Our fundraising return ratio was considerably improved – we raised nearly £7 for every £1 invested in fundraising.

However, for the first time in three years, our income was below £1 million. This is despite being able to celebrate another astonishing Big Give Christmas Challenge success. The generous support of our matchfunders, including our champion *Candis*, meant that donations made during this seven-day campaign were doubled, raising £144,425 in total.

The outlook for charity fundraising in general, and thus for ourselves, is challenging in the current climate and we see activities such as the Big Give continuing to play a critical role in our funding.

Recognising the difficult fundraising environment coupled with both the likely impact of lockdown on people with M.E. and the potential for increased demand from those with post-viral Covid-19, we have had to make some tough decisions since year end. We have restructured the way we offer our services to offer a more integrated approach through our new Crisis, Support and Advocacy Service, leading regrettably to four redundancies in July and a number of planned posts deleted. Our thanks go to those individuals for their contributions to people with M.E. during their time at Action for M.E.

I must offer my thanks to my predecessors – Jonah Grunsell, who stepped down in October 2019, and Matt Symonds, who took the chair on an interim basis until my appointment.

We believe now that we have a streamlined service that provides a strong platform to manage any increases in demand for our services. This is our chief concern – to be able to sustain our vital services and support and to keep adults, young people and families with M.E. at the heart of what we do.

None of this would be possible without those who give their time, energy, experience and donations to support our work. To all the trusts, foundations, individual donors, Supporting Members, fundraisers, legacy givers, volunteers, advocates, campaigners and supporters, and our staff, I say a sincere and grateful thank you. We will not let you down.



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



“This is our chief concern – to be able to sustain our vital services and support and to keep adults, young people and families with M.E. at the heart of what we do.”

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On the cover: Lloyd developed M.E. when he was 10. His mum, Lisa, got in touch with us when Lloyd had a difficult transition from school to college. "When I contacted your service, I was beginning to feel quite overwhelmed," says Lisa. "It was such a breath of fresh air to find somebody that had time and wanted to listen." We were able to support them with their Education, Health and Care Plan and find alternative education pathways that Lloyd can take when he is well enough to return to education. Because of you, we can continue to be here for families like Lloyd and Lisa's.



Our year in numbers



94%

of families felt better informed after receiving our support

25

Average number of times every day our booklets, factsheets and support resources were accessed to provide vital, trusted information.

"You made me realise I was not alone at a time when I felt isolated and without anyone who understood."
Service user, August 2019



£144,425

raised through Big Give from 492 donors

3,630

Average daily reach on Facebook

"Your Facebook page has been a massive revelation. It's a relief to hear that others are also in these situations. Most importantly, you are not alone."

Carole, on Facebook

1,230

Number of active threads over the year in our M.E. Friends Online forum, including the "Get your big hugs here" thread, now running for more than three years.

"This forum has given me a sense of purpose on days and weeks where I have struggled to do much at all. It truly feels like a family where we are each listened to and cared for."

M.E. Friends Online forum user



9,125

reached through our support literature

1,820

Number of times people with M.E. accessed one-to-one information and support by phone or email – that's six times every working day.



£10,628

Total raised by our nine Walk with M.E. teams, who clocked up nearly 23 million steps over 100 days between them.

"Action for M.E. have played a vital role in my recovery and they have given me the chance to share my story in a way to help others. I'll forever be grateful."

Walk with M.E. fundraiser Alice



50

MPs who pledged to work with us to improve the lives of people with M.E., after we contacted every General Election candidate in December, including Kerry McCarthy, pictured with our Trustee Phil Murray

180

teachers and young people engaged in the 'how can I help?' sessions

4,038

people took part in the Big Survey, giving us a great insight about life with M.E. in the UK



"Little things that years ago took me five minutes to do can take me all day now. Even cooking a basic meal and eating correctly is so challenging. I cheat a lot with cooking, like putting fresh vegetables in tins of beans. This is how I get by. I feel ashamed that from being fully active, and going above and beyond, I have gone to scraping along, just trying to do the basics, and not even accomplishing that."

Sally (not her real name), 47, Kent. See bottom of the next page for how we helped.

You are not alone: we're here for people with M.E. of all ages and their families.

Between April 2019 and March 2020, people with M.E. accessed one-to-one support from our friendly, experienced Information, Support and Welfare team 1,820 times – that's six times every working day.

Children and young people with M.E., and their families, also get support to access school and healthcare in a way that works for them.

"You have been the light that has helped us navigate these most challenging of months, providing bridges between agencies and disciplines, with your experience, expertise and calm, unwavering support."

Sharon, whose son has M.E.

Thousands connect through our peer-support communities.

Some are online: on social media, and our peer-support forums for adults and young people, with more than 4,300 registered users.

But not everyone with M.E. is able to use a screen. We've built communities around our membership magazine *InterAction* and Christmas Angels project, allowing people with M.E. to connect by post via the Action for M.E. office, reducing the isolation that so often comes with M.E., and showing them they are not forgotten.



"A big thank you for my lovely Christmas card and gorgeous knitted angel received today. It actually put a smile on my face."
Judith

People with M.E. use our information and resources to make important decisions about their care.

Making informed decisions about how to manage symptoms is challenging when there's so much information out there.

Using data from our Big Survey (see p 8-9), we have updated key resources and website information to reflect the experiences and insight of more than **4,000** people with M.E.

Our resources were downloaded 8,500 times, and 800 hard copies sent by post.

100% of adults would recommend our service to others

94% of families felt more informed about the issue they contacted us about

86% of families would feel more confident dealing with a similar issue in future

83% of adults had increased understanding of their rights and other support available to them

77% of adults had increased knowledge of other services to access.

People with M.E. frequently tell us that the need to explain, over and over, what M.E. is and how it affects them is one of the most alienating things about it.

"This continual pressure to explain has a negative effect on your self-esteem and ability to accept and make the best out of life. One of the valuable sides of having a mentor is that they fully comprehend."

Mentee, matched with mentor as part of our ongoing Mentor M.E. project in Scotland

This year, nearly 30 mentors and mentees accessed support from us and each other, to improve self-management skills, increase confidence and well-being, and feel less isolated.

"It has been brilliant for both of us. It really has been a two-way street as we've exchanged information on what has worked for us. My mentor has suggested options I would not have considered."

Mentee

Around 70 people with M.E. came to our Meet M.E. information, support and mentoring events in June and October, telling us that they loved "making connections and talking about my health, which I never really do."



Resources produced by our pilot regional advocacy service in the South West and Midlands, supported 393 people to help inform decisions about their support and care.

We provided detailed, direct advocacy to 80 individuals, many marginalised by severe M.E., on a range of different issues. As a result:

- half told us they have increased access to services and support, and better financial well-being, as a result of our support
- one in three told us they have improved their health.

K was told she did not meet the criteria for a bus pass, and needed a Blue Badge. With support from our advocate, K felt fully prepared to attend the assessment and address the assessor's unwillingness to understand M.E. Two weeks later, K was awarded a Blue Badge, and successfully applied for a bus pass.



"A big thank you for your support and amazing letter. This will have a huge impact on my day-to-day life. I can nip out to the shops, not worrying about the cost (bus fares are so expensive). More independence. Always pushing forward on my next goal."

K, advocacy service user

The people around those with M.E. at work and school have the power to make a huge difference. Working with young people with M.E. and their parents, we developed resources and training for our Educate M.E. project in Scotland, aimed at teachers and pupils.

Our "How can I help?" sessions in November and January drew **80 teachers and pupil support and inclusion officers**, alongside 100 young people.

"I didn't really have a good understanding of M.E. at the start of today. I feel that now I am more aware of the symptoms, barriers and supports." Teacher who attended our "How can I help?" session

After she called us for support, Sally (not her real name), said *"I put so much energy into masking how bad things are from people around me. It was such a relief to hear from other people via InterAction that I am not alone. You helped me with advice when I've been struggling. You are a fantastic service, being at the end of the phone. It is so needed. I also appreciate the awareness-raising. We want others to learn what we've gone through – it makes it not worthless."*



M.E. still carries a stigma. We stand alongside people with M.E. to fight ignorance, injustice and neglect.

More than 4,000 children, young people and adults with M.E. shared their insight and experience in our Big Survey, launched in May 2019.



94% of respondents said they stopped or reduced social contact



49% reduced or lost capacity to drive.



33% require full or part-time care.



88% stopped or reduced household tasks.



26% are no longer able to leave home independently.



83% stopped or reduced paid work.

We have been able to use our Big Survey findings to reiterate clear messages about the urgent need for appropriate care and support for people with M.E., and insist that the experiences of people with M.E. are heard and acted upon.

Crucially, this includes the revision of the National Institute for Health and Care Excellence's UK (NICE) diagnosis and management guideline for M.E., now delayed until spring 2021.

We ensured the experiences of children and young people with M.E. are considered in the development of the new NICE guidelines, by working with Oxford Brookes University to promote and recruit to a focus group.

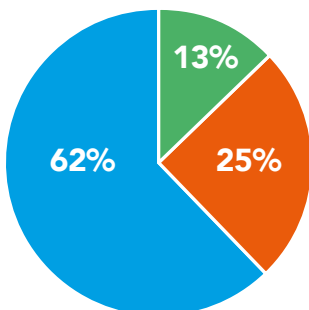
We used Big Survey data in responding to NICE's autumn consultation asking for experiences of people "who have had interventions for M.E./CFS."

"Supporting previous findings by Action for M.E. and others, our Big Survey found that the interventions being recommended by the NICE guideline – cognitive behavioural therapy (CBT) and graded exercise therapy (GET) – are, in a significant number of cases, making symptoms worse. This is the case even when these approaches are delivered by an M.E. specialist."
Action for M.E. response to NICE consultation, October 2019

Just **7%** of children and young people and **16%** of adults are obtaining a diagnosis within the recommended Government guideline's timescale of three months and four months respectively. Almost one in five adults (18%) waited more than six years for a diagnosis.



How did respondents describe their level of M.E. severity?



13% Severely affected
25% Moderately affected
62% Mildly affected

Just over one in 10 respondents described themselves as severely affected.

99% of respondents said they experience post-exertional malaise either always, usually or sometimes. Simple physical or mental activities, or combinations of activities, can leave people with M.E. feeling utterly debilitated. This is also known as post-exertional malaise (sometimes called 'payback').

"If teachers and doctors had more knowledge on realistic life with M.E., things would be so much easier. It was heartbreaking to hear someone who is supposed to understand me the most dismiss my symptoms."
Big Survey respondent under 18, London

Using Big Survey data, we have brought the voices, views and wishes of people with M.E. to:

- Ed Scully, Director of Primary and Community Health Care, Department of Health and Social Care
- Rachel Crowder, Chief Therapist Officer with the Welsh Government
- NICE Guideline Development Group
- Scottish Petitions committee
- NHS Inform Scotland.

Better informed policy-makers and professionals means more appropriate support and care.

We co-created a two-page briefing for healthcare professionals at the Royal College of GPs (RCGP) conference, working with Forward ME. With information on post-exertional malaise, our serious concerns about GET and CBT, and the importance of rest, pacing and medication for individual symptoms, we gave out hundreds of copies over this three-day event in October.

"I saw you at last year's conference and the information you gave me has changed the way I work with people with M.E." GP who came to our joint Forward ME stand at the RCGP conference



M.E. stories matter: we support people with M.E. to get them in front of a wider audience.

Around 10.4 million people had the chance to see our Big Survey statistics, interviews, letters and stories, bravely shared by people with M.E. of all ages across the UK, in outlets including Bella and Candis magazines, BBC news, Daily Express, Guardian, Independent, Vice and UNILAD.

"Despite the shocking data, the severity of ME/CFS is not currently being reflected in the way government leaders prioritise funding and – frighteningly – many doctors are still unsure of how to diagnose and manage this condition."

Journalist Julia Banim, Vice, May 2019



Biggest audience Sonya spoke out in the Guardian about inappropriate JobCentre advice in October 2019, reaching 1.9m readers.



Specialist subject We worked collaboratively with Naomi, who was training as a nurse when she became ill with M.E. to produce content for Royal College of Nursing's Primary Health Care; we also placed stories in Northern Ireland Healthcare Review, Scottish Healthcare and Wales Healthcare journals, targeting health professionals.

M.E. is a non-visible disability. We help make it more visible.

In July, we successfully lobbied the Department of Transport to improve its new Blue Badge guidance, which had referred to hidden disabilities as "non-physical," ignoring the reality of living with M.E./CFS or other non-visible illnesses such as Parkinson's.



Scotland's first Draft National Action Plan on Neurological Conditions chose to overlook consultation data from the 33% of responses from people with M.E. We successfully lobbied the Scottish Government to engage with the M.E. community via a Scottish Health Council survey of M.E. in Scotland in February.

We stamp out stigma.

Our most viewed and shared social post of the year was a PDF summary of scientific evidence "for the non-believers" collated by Dr Mark Guthridge. This single Facebook post was shared 900 times, and reached 74,000 people.

For the non-believers

This excellent summary of the scientific evidence for M.E. was shared on Twitter by Research Scientist, Dr Mark Guthridge.

M.E. patients face disbelief that they are sick. Many are told that they are simply tired, stressed, anxious, depressed, lazy or malingering. How can people with M.E. respond to such disbelief and lack of understanding?

Below are seven evidence-based scientifically supported findings that you can use to inform those who don't understand that M.E. is a multi-organ, systemic and severely debilitating illness.

These findings demonstrate that M.E. patients have a range of biochemical impairments that are:

- a) simply not possible to fake
- b) not due to deconditioning
- c) not due to depression.



1. People with M.E. have deficiencies in three organs important for the body's hormonal balances called the hypothalamic-pituitary-adrenal axis. Importantly, the deficiencies observed in M.E. patients are quite different to that seen in depression.
2. Cognitive problems are widely observed in M.E. where the brain's ability to process information is slowed and memory is impaired. Importantly, the impairments are simply not consistent with the presence of psychiatric disorders.
3. The latest fMRI imaging findings show that the brains of people with M.E. have different challenges, and in memory. M.E. patients also have altered connectivity between different brain regions, possibly explaining why they have cognitive impairment.
4. The latest brain imaging studies also demonstrate that people with M.E. have widespread brain inflammation (neuroinflammation) and increased brain lactate. Spinal fluid in M.E. also contains increased levels of proteins involved in tissue injury and repair.
5. It's not complicated! People with M.E. lack "energy" because their cells have a problem generating (and/or possibly using) energy from oxygen (aerobic metabolism), autors (anaerobic metabolism), and oxidation) and
6. Many studies of M.E. patients problems. For levels of pro signalling proteins significantly lower with M.E. and patients have of cytokines
7. Lastly, multiple studies have shown that with M.E. be have increased proinflamm a lower heart pressure an metabolism



We bring more people and more investment into M.E. research

“Nearly eight years ago, in my first week with Action for M.E., Prof Stephen Holgate set out his expectation of me in my new role. He told me that my predecessor had helped plan the idea of the UK CFS/ME Research Collaborative (CMRC) to bring together UK researchers, to increase investment in research. He wanted to know who we were inviting to the first meeting in just two weeks’ time. This no-nonsense approach is what led to the £3.2m funding announced this week for the DecodeME study, the world’s largest DNA M.E. study.”

Sonya Chowdhury, Chief Executive Action for M.E.

Providing Secretariat support for the CMRC since 2012, we have organised six annual conferences, with this year’s taking place just before lockdown.



18

International speakers presenting the latest M.E. research and global collaborations



2,560

Number of times our films of CMRC speakers have been viewed on YouTube

Made possible by donations to our Clare Francis Research Fund, we’re investing in biomedical PhD studentships, bringing researchers into the field early in their career.



With match-funding from Brighton and Sussex Medical School, we granted funding to Prof Neil Harrison, now based at Cardiff University, to recruit a PhD student to study brain activity and inflammation in M.E. and fibromyalgia using state-of-the-art imaging.

“We will be presenting three posters and one talk at an international brain and body conference; my supervisor, Dr Jessica Eccles, will present at an international fibromyalgia conference. One of the most important things I’ve taken on board is the importance of listening to patients. I have felt privileged to hear their stories. I sincerely hope the work we are doing will have a real impact on patient experience in the future, by enhancing scientific and public understanding of M.E.”

Marisa Amato, PhD student



Jointly funded by the Scottish Government Chief Medical Office, our project at Edinburgh University compares immune cells (T cells) from people with M.E. with those from controls.

“We hope that this will banish any remaining doubt about the biomedical base of M.E./CFS among clinicians, by equating it with better understood autoimmune conditions and diseases. As M.E. is so poorly understood, I hope my contribution will at some point help the many people with this illness around the world.”

Joshua Dibble, PhD student

This funding was granted to Prof Chris Ponting, with whom we are now co-leading DecodeME, the world’s largest DNA M.E. study. It needs 20,000 people with M.E. to take part, using “spit-and-post” sample kits. The study will begin in March 2021.

For every £1 we invest in fundraising, we raise nearly seven times that in donations

Our amazing supporters bake, buy, bike, craft, canoe, walk, wheel, run and roll to ensure we can continue our vital work.



£63,162 raised by bakers, crafters and other community fundraisers



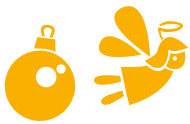
£35,941 raised by runners, cyclists, trekkers and skydivers



£9,743 raised by those who took part in our raffles and Unity Lottery



£6,156 raised by payroll givers



£3,653 from sales of our range of Christmas cards



£10,628 raised by our 9 Walk with M.E. teams

"Action For M.E. do such important work to support people with M.E. and their families. I'd been thinking about fundraising for a while and Walk with M.E. seemed like the perfect fit. I can join in with the small amount of steps I can do, and my family and friends can be a part of it as well. Fundraising like this really helps people to realise there is something really important they can do to help."

Holly, who has M.E.

Meet some of our amazing supporters



Alex, 10 (pictured above) shared her story as part of our Big Give Christmas Challenge campaign, offering hope to other young people, and sharing how the right support is so important.

"Children with M.E. are the most determined, strong, inspiring incredible people. Well done Alex on making this video."

Catherine Sampson, on Facebook

Our brilliant Bath Half marathon team - Tom, Katie, Sophie and Ed - raised more than £1,000.



Miyah (pictured left) is a carer for her mum, who has M.E. Miyah organised a sponsored haircut for her 10th birthday and raised more than £700.

Dave, landlord of the Thunderbolt in Bristol, hosted a fundraising gig with all acts performing for free.

Elinor, who has M.E., asked her friends and family to donate to her 21st birthday Facebook fundraiser. She was diagnosed in 2013.



"Whilst I'm thankful that my 21st birthday will be a little different than my 14th, I am reminded every day that this condition can affect me at any time, and that it can affect anyone. We all know people with M.E., although many of us don't realise. Let's give a voice to those unheard."

Alice (pictured left) ran the London Marathon in honour of her best friend Katie who had M.E., and sadly died in 2015. Alice tells us that "although Katie's death was unrelated to her M.E. diagnosis, the charity helped her lots throughout her life."

In the final year of our 2016 – 2021 strategy we hope to achieve:



2,300

Enquiries from adults, children, Carers and professionals responded to through our information and support services

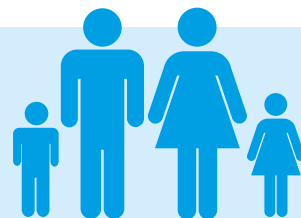


8,500

Factsheets, booklets and other resources will be accessed by people with M.E. to support their self-management and increase access to relevant and timely information about M.E.

4,100

Adults, parents, Carers, children and young people will access peer support through our online forums and peer support projects



125

Families will receive support and advocacy



Young people will attend workshops helping to overcome their isolation and build positive relationships with other young people with M.E.



12

Local M.E. support groups will be supported to continue their vital local work with people with M.E.



200

Adults will receive Advocacy support, helping to ensure their voices are heard, rights and respected and to increase access to services

How we raised and spent our income this year

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

This year, we spent 89% of our income on **charitable activities**; including our one-to-one support services, our campaigning and influencing work, and our investment in collaborative biomedical research.

To deliver effectively, we need **committed and dedicated staff** who bring the right skills, knowledge and experience to every area of our work. That's why two thirds (66%) of our total gross expenditure is on staff salaries (including employer National Insurance and pension contributions).

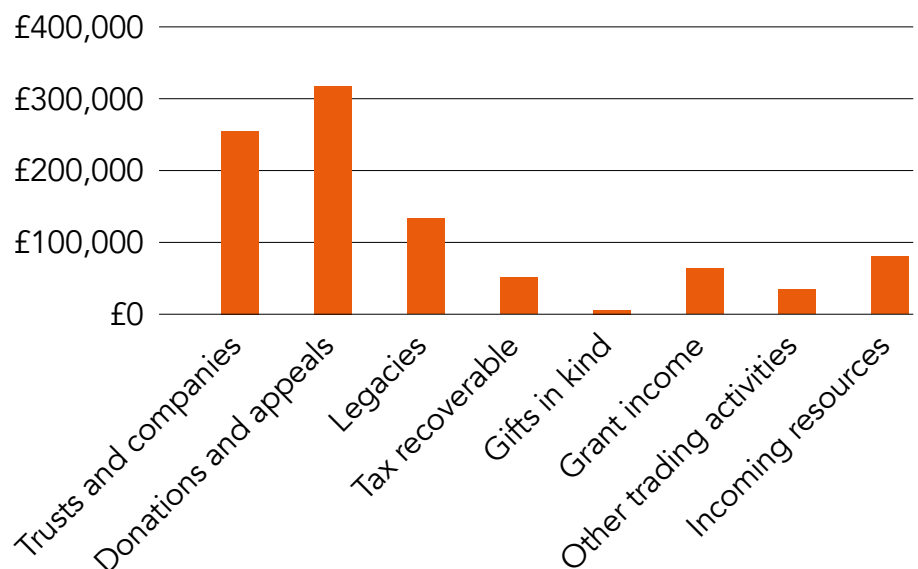


In our strategy, we promise to raise £3 to £5 for every pound we spend on fundraising, growing our income streams to deliver more services and support, and greater change.

During 2019 – 2020, we raised £6.91 for every £1 invested in fundraising.

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

Our **recorded total income** for the year was £949,527, down 12% from the previous year. We did not hold our large fundraising event, Dragonfly Dinner, this year.



Overall expenditure was £985,977, a decrease of 21% from the previous year as a result of pausing our International Advocacy work and some staff posts being unfilled for periods of the year. The net result is an overall deficit of £36,450. The charity ended the year with the equivalent of 3.6 months unrestricted operating costs in unrestricted reserves. The Action for M.E. policy to is to hold three to five months of unrestricted operating costs.

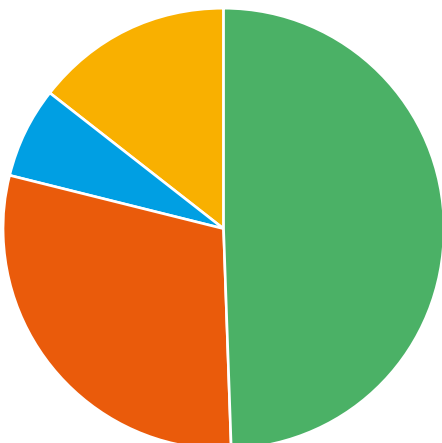
This year, we spent:

£489,961 on our one-to-one support services for adults, young people and families with M.E.

£289,795 on our campaigning and influencing work

£65,230 on our investment in collaborative biomedical research

£140,991 on fundraising (cost of generating voluntary income at £137,470, plus goods and trading at £3,521)



Statement of financial activities

We remain the only M.E. charity in the UK providing support to people with M.E. of all ages. Despite seeing our income decrease by 12% from the previous year, our committed team of staff and volunteers responded to 351 more requests for information and support than in 2018 – 2019. The last two weeks of this financial year saw a sharp increase in people needing support, as the country prepared to enter the Coronavirus lockdown in late March.

Following the global coronavirus pandemic and the subsequent UK lockdown announced on 23 March the charity has been impacted in the following ways.

We have undertaken a budget reforecast exercise and removed 51% of expected income from the budget. All community fundraising income was removed as large fundraising events such as the London Marathon were cancelled or postponed. Other income streams including donations, legacies and trusts have been reduced.

The charity placed six staff on the government's furlough scheme (April – June) and has restructured, removing seven posts through redundancy and deleting unfilled posts. The charity has been able to maintain all regular payments e.g. business rates. Our head office in Keynsham has been closed during this time to protect staff, volunteers and service users.

The charity has drawn up budgets and a cashflow for the next 12 months whilst the pandemic eases in the UK, including designating significant funds to manage the ongoing economic uncertainty as a result of Covid-19, and the predicted increase in M.E./CFS as seen following the SARS epidemic. The Trustees are closely monitoring the situation and have taken into account the continuing viability of the organisation and have

reduced costs where possible. As a result of this the Trustees have concluded that the charity has adequate resources to continue in operational existence for the foreseeable future and there are no material uncertainties about the charity's ability to continue as a going concern.

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

While our income dropped below the £1million mark for the first time since 2017 to £949,527, Action for M.E. has again achieved a sound underlying financial performance, ending the year with a small deficit of £36,450; this is well within our unrestricted reserves policy (see below). During the year the charity had 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. This year's Big Give Christmas Challenge proved to be the most successful of the three campaigns we have participated in to date, raising £144,425 to support our vital work to end the ignorance, injustice and neglect experienced by people with M.E.

Overall expenditure was £985,977, a decrease of 21% from 2018 – 2019. Our International Advocacy work was paused in September 2019, resulting in savings which were supplemented

by a number of budgeted staff posts being unfilled for parts of the year. At year end, unrestricted general reserves were £219,645 (down £144,099). A further £90,000 of free reserves has been designated by the Board of Trustees to manage the impact of any future Covid-19 lockdowns, and to support the likely increase in demand for our services over the next 12 months, as scientists predict an increase in M.E. diagnosis as a result of Covid-19 post-viral complications.

Restricted reserves were £216,337 (up £17,649) which will be expended over the course of the next year on biomedical PhDs and the Clare Francis Research Fellowship. We continue to monitor our level of reserves to ensure we can maximise the work we do while ensuring the charity has a strong medium-term financial position.

We aim to raise £3 to £5 for every pound we spend on fundraising, growing our income streams to increase the amount we can spend delivering our services and support. During 2019 – 2020, we raised £6.91 for every £1 invested in fundraising (up from £4.20 last financial year).

Balance sheet

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

Funding sources

The principal funding sources for Action for M.E. are charitable trusts, legacy giving, community fundraising and events, Supporting Membership income, and individual gifts. Other funding sources include the Masonic Charitable Foundation, Scottish Government grants, Gift Aid, and Christmas card sales.

Despite having a diverse and broad funding base, like many charities, we anticipate a challenging year of

Statement of financial activities

fundraising in 2020 – 2021 as the full economic impact of Covid-19 is felt across the sector and beyond.

This year, we are enormously grateful to John Swire 1989 Charitable Trust, Philip King Charitable Trust, Masonic Charitable Foundation, The De Laszlo Foundation, The Henry Smith Charity and The Sir James Reckitt Charity for funding our support and research work.

Investment policy

Aside from retaining a prudent amount in reserves each year, most of the charity's funds are spent in the short term so there are few funds for long-term investment. The charity has an investment policy which currently uses the COIF Charities Investment Fund to provide a short term interest-bearing account that optimises the balance between flexibility and rate of return.

Reserves policy

The current policy is to maintain the level of 'free' unrestricted general funds at no less than three times, and no more than five times, the monthly unrestricted running costs of the charity. The charity held at year end the equivalent of 3.6 months of operating costs in unrestricted general funds at an average monthly spend rate of £60,997. In addition, the charity held designated funds representing 1.5 months of operating costs to manage the future impact of Covid-19 as described earlier.

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 biomedical research.

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' annual report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally

Accepted Accounting Practice). Company and charity law requires the Trustees to prepare financial statements for each financial year.

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

In preparing those financial statements the Trustees are required to:

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

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

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of

fraud and other irregularities. The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website, the Online M.E. Centre.

Legislation in the United Kingdom governing the preparation and dissemination of the financial statements and other information included in annual reports may differ from legislation in other jurisdictions.

Auditor

Moore (previously known as Moore-Stephens) was re-appointed as our auditor at the 2019 Annual General Meeting.

Provision of information to Auditor

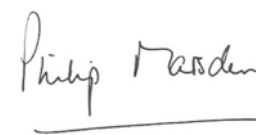
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish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

Small company provisions

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



Roger Siddle
Chair of Board of Trustees
and Directors



Philip Marsden
Director and Treasurer

Approved by the Board on Thursday
13 August 2020

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 5 to 11.

Trustees

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

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

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

Our committees

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

- The Audit, Finance and Fundraising Committee meets quarterly and reviews finances, risk controls, audit requirements, fundraising, and income generation activity to support and grow our work.
- The Policy Group meets quarterly and provides a steer for the charity's policy and influencing work at local, national and international level.
- The Research Panel meets at least annually and monitors the charity's research-funded activity.
- The Remuneration and Nominations Committee meets as and when required, to make recommendations to the Board on senior appointments and related significant employment contract issues.

All staff members, including the Chief Executive, have performance targets that link directly to the charity's strategic objectives. Progress against these is monitored through regular one-to-one meetings and an annual performance review. An annual outcomes summary is provided to the Board to assist with performance management responsibilities. All Trustees give their time voluntarily and received no benefits from the charity. Any expenses reclaimed from the charity are set out in the notes to the accounts.

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

Supporting Members vote on new appointments and the re-election of existing Trustees, with results subsequently confirmed at our Annual General Meeting (held this year in October 2019). 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. (see p 9), Advice Centres for Avon, Disability Rights UK, Health Conditions in Schools Alliance, 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 Collaborative (see p 10), which led to the establishment of the M.E./CFS Biomedical Partnership, the group leading DecodeME.

Volunteers

Our support, services and campaigns are amplified and enriched by a range of clinical, scientific and other professional advisors on a pro bono basis.

In addition, we are lucky to have the support of many wonderful volunteers who add huge value to our work, and help us reach even more people with M.E.

Our peer-support services offered by our Young Person's Community are driven by young volunteers who:

- write stories, reviews, pictures, poems and jokes for our *Cheers* e-magazine
- moderate our Young Person's Forum, keeping it safe, fun and secure for all users
- send letters to their severely affected peers, without the expectation of a reply, letting them know they haven't been forgotten.

Just after year end, we began recruiting young volunteers for our Breaking Isolation steering group, a project funded by Children in Need.

Our services and projects for adults are also supported by a range of volunteers, including:

- those working at home and in the office to ensure our membership, fundraising, communications and campaigning work is effective
- writing, proofing and recording content for our membership magazine, *InterAction*, described by many as a lifeline
- our volunteer peer mentors, sharing mutual support and guidance to mentees through our Mentor M.E. project in Scotland

- our professional volunteer advocates, trained to support people with M.E. to have their rights, wishes, and needs heard as part of our regional advocacy service, now expanded UK-wide.

We are enormously grateful, and could not do what we do without the time, energy, experience, insight and dedication of all our volunteers.

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 34. The Company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the Company being wound up members are required to contribute an amount not exceeding £1.

Fundraising policy

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

The charity recognises the need to conduct its fundraising within the context of recognised standards set out in the Institute of Fundraising's Code of Fundraising Practice, the Data Protection Act 2018 and the CAP Code (Committee of Advertising Practice). We do not employ external professional fundraisers or companies.

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

independence and integrity of the charity; and that all activities must be carried out with honesty and integrity, with employees never knowingly misleading supporters. Any confidential information obtained must always be protected, and the trust of our supporters must not be violated. The policy also sets out the way in which we deal with fundraising complaints.

Risk

The Operations Director (in post from July 2019) and the Chief Executive have been responsible for the Risk Register, which is reviewed regularly by the Audit, Finance and Fundraising Committee and annually by the Board. Risks are categorised in a way that enables us to see the cumulative impact of risks and ensure that we take action to protect the quality of our work, reputation and income.

For example, by closely monitoring our income, with monthly reviews and reports to Trustees, with actions identified to minimise expenditure and increase income, we mitigate the risk that our income falls below projections. Safeguarding training covering both vulnerable adults and young people is included within the organisational induction policy, with refresher training delivered annually.

No serious incident reports were made to the Charity Commission regarding activity in April 2019 to March 2020.

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

Opinion

We have audited the financial statements of Action for M.E. (the 'charitable company') for the year ended 31 March 2020 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 2020 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

We have nothing to report in respect of the following matters in which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate, or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the trustees' report.

We have nothing to report in respect of the following matters where the Companies Act 2006, the Charities Act 2011 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

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

Responsibilities of trustees

As explained more fully in the trustees' responsibilities Statement set out on page 15, 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.

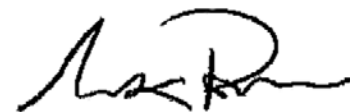
Auditor's responsibilities for the audit of the financial statements

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.

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

13 August 2020

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2020

	Notes	Unrestricted funds (£)	Restricted funds (£)	Total 2020 (£)	Total restated 2019 (£)
Incoming resources					
Incoming resources from generated funds:					
Donations and legacies	3	558,762	269,916	828,678	823,304
Other trading activities	3	33,025	1,750	34,775	161,305
Investment income	4	1,267	1	1,268	1,134
Incoming resources from charitable activities	3	84,806	–	84,806	90,712
Total incoming resources		677,860	271,667	949,527	1,076,455
Resources expended					
Costs of generating funds:					
Costs of generating voluntary income	5	134,436	3,034	137,470	264,972
Fundraising trading: costs of goods sold and other costs		3,521	–	3,521	4,661
Charitable activities	5	594,002	250,984	844,986	973,177
Total resources expended		731,959	254,018	985,977	1,242,810
Net movement in funds	12	(54,099)	17,649	(36,450)	(166,355)
Reconciliation of funds					
Fund balances at 1 April 2019		363,744	198,688	562,432	728,787
Fund balances at 31 March 2020		309,645	216,337	525,982	562,432

All incoming resources and resources expended derive from continuing operations. The notes on p 23 to 33 form an integral part of these accounts.

Balance sheet

As at 31 March 2020 (company registered number 2906840)

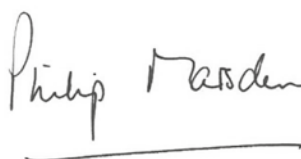
	Notes	2020 (£)	restated 2019 (£)
Fixed assets			
Tangible assets	9	27,181	25,591
Net current assets			
Debtors	10	130,037	86,382
Cash at bank and in hand		421,808	574,389
Total current assets		551,845	660,771
Creditors: Amounts falling due within one year	11	(53,044)	(123,930)
Net current assets		498,801	536,841
Total assets less current liabilities		525,982	562,432
Capital and reserves			
Unrestricted funds:			
General funds	12	219,645	363,744
Designated funds	12	90,000	–
		309,645	363,744
Restricted funds	13	216,337	198,688
Accumulated funds		525,982	562,432

The accounts for prior year have been adjusted by transactions related to the CFS/ME Research Collaborative of which Action for M.E. does not hold overall control. Action for M.E. is the founding member of the collaboration and provides a secretariat service to its board. The prior year has been restated to provide a like for like comparison with the accounts ending 31 March 2020 as set out in note 18 to the accounts.

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 23 to 33 form an integral part of these accounts.



Roger Siddle
Chair of Board of Trustees and Directors



Philip Marsden
Treasurer

Approved by the Board of Trustees Thursday 13 August 2020

Action for M.E. cash flow statement for the year ended 31 March 2020

		2020	restated 2019
Net cash flow from operating activities	See note a below	(143,610)	(85,420)
Net cash flow from investing activities	See note b below	(8,971)	(28,121)
Net decrease in cash and cash equivalents		<u>(152,581)</u>	<u>(113,541)</u>
Cash and cash equivalents at beginning of period		574,389	687,930
Cash and cash equivalents at end of period		<u>421,808</u>	<u>574,389</u>

Notes to the cash flow statement

a Cash flows from operating activities

	£	£
Net movement in funds	(36,450)	(166,335)
Depreciation	8,649	5,810
Financial income	(1,268)	(1,134)
	<u>(29,069)</u>	<u>(161,659)</u>
(Increase)/decrease in debtors	(43,655)	25,543
(Decrease)/increase in creditors	(70,886)	50,696
NET CASH FROM OPERATING ACTIVITIES	<u>(143,610)</u>	<u>(85,420)</u>

b Cash flows from investing activities

	£	£
Purchase of tangible fixed assets	(10,239)	(29,255)
Interest received	1,268	1,134
NET CASH FROM INVESTING ACTIVITIES	<u>(8,971)</u>	<u>(28,121)</u>

Analysis of changes in Net Funds

	At 1.4.2019 (£)	Cash Flow (£)	At 31.3.20 (£)
Cash at Bank	574,389	(152,581)	421,808
Total	574,389	(152,581)	421,808

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.

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

The Charity operates a partial-exemption method for the recovery of certain VAT. Irrecoverable VAT is included in support costs.

Operating lease agreements

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

Financial instruments

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

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

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

- Apportionment of staff time on specific activities has been made in the absence of formal timesheets and therefore based on the role profiles and work-plans of the individuals, as in previous years.
- A Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy in the year has been made on the basis that, as in previous years, small projects had an agreed 'in kind value' of £2,000.
- A further gift in kind has been recorded for some photography support of £2,000.
- The valuation and recognition of pending legacies throughout the year and specifically at the year-end is based on the charity's entitlement to funds, the availability of sufficiently reliable estimates of the amount indicated for the legacy and the probability that it will be received.

3 Details of incoming resources

	Unrestricted funds (£)	Restricted funds (£)	Total 2020 (£)	Total 2019 (£)
Donations and legacies				
Trusts and companies	90,348	162,913	253,261	252,286
Donations and appeals	282,128	35,547	317,675	343,235
Legacies	130,995	–	130,995	97,039
Tax recoverable	53,291	4,260	57,551	63,041
Gifts in kind	2,000	3,493	5,493	4,000
Grant Income	–	63,703	63,703	63,703
	558,762	269,916	828,678	823,304
Other trading activities				
Lotteries and raffles	9,743	–	9,743	11,598
Christmas cards	3,653	–	3,653	4,045
Supplement commission	1,688	–	1,688	2,000
Merchandise	368	597	965	1,039
Events	750	–	750	125,496
Other	16,823	1,153	17,976	17,127
	33,025	1,750	34,775	161,305
Incoming resources from charitable activities				
Subscriptions	82,906	–	82,906	88,700
Charity journal	1,568	–	1,568	2,116
Information and publications	332	–	332	309
	84,806	–	84,806	90,712

Details of 2019 income	Unrestricted funds (£)	Restricted funds (£)	Total 2019 (£)
Donations and legacies			
Trusts and companies	154,686	97,600	252,286
Donations and appeals	290,593	52,642	343,235
Legacies	97,039	–	97,039
Tax recoverable	52,874	10,167	63,041
Gifts in kind	4,000	–	4,000
Grant Income	–	63,703	63,703
	599,192	224,112	823,304
Other trading activities			
Lotteries and raffles	11,598	–	11,598
Christmas cards	4,045	–	4,045
Supplement commission	2,000	–	2,000
Merchandise	261	778	1,039
Events	125,496	–	125,496
Other	17,127	–	17,127
	160,527	778	161,305
Incoming resources from charitable activities			
Supporting Membership	88,287	–	88,287
Membership magazine	2,116	–	2,116
Information and publications	309	–	309
	90,712	–	90,712
4 Investment income			
		2020 (£)	2019 (£)
Interest from cash investments in the UK		1,268	1,134
		1,268	1,134

5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2020 (£)	Total 2019 (£)
Costs of generating voluntary income				
Staff costs	28,420	–	28,420	26,627
Direct fundraising costs	10,934	3,034	13,968	109,723
Support costs – see below	95,082	–	95,082	128,622
	134,436	3,034	137,470	264,972
	Unrestricted funds (£)	Restricted funds (£)	Total 2020 (£)	Total 2019 (£)
Charitable activities				
Information and support services	303,597	186,364	489,961	633,821
Campaigning and influencing work	279,086	10,709	289,795	233,220
Collaborative biomedical research	11,319	53,911	65,230	106,136
	594,002	250,984	844,986	973,177

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

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

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

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

Office costs include £2,000 (£4,000 in 2019) for professional services in kind.

	2020 (£)	2019 (£)
Governance costs		
Administrative salaries – based on time spent	13,641	18,986
Indemnity insurance for Trustees	2,314	1,603
Governance training and travel	2,674	165
Trustees' expenses	3,275	2,486
Meeting room hire and refreshment costs	5,268	4,650
Auditors' fees	6,250	6,250
Professional fees	400	299
Design and printing	1,312	1,478
Postage and office supplies	168	125
	35,302	36,042

	2020 (£)	2019 (£)
Grant activities		
The University of Sussex – PHD in Biomedical Research	15,243	15,094
The University of Edinburgh – PHD in Biomedical Research	2,306	36,000
	17,549	51,094

Details of 2019 expenditure	Unrestricted funds (£)	Restricted funds (£)	Restated 2019 (£)
Costs of generating voluntary income			
Staff costs	26,627	–	26,627
Direct fundraising costs	108,970	753	109,723
Support costs – see below	128,622	–	128,622
	264,219	753	264,972
Charitable activities			
Information and support services	482,113	151,708	633,821
Campaigning and influencing work	223,713	9,507	233,220
Collaborative biomedical research	12,368	93,768	106,136
	718,194	254,983	973,177

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

Activity	Activities undertaken directly	Support costs as below	Total (£)
Information and support services	282,501	199,612	482,113
Campaigning and influencing work	133,925	89,788	223,713
Collaborative biomedical research	–	12,368	12,368
	416,426	301,768	718,194

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

	Governance costs as below	Admin costs finance	Property management	Office management	IT admin costs	Total £
Support costs						
Communications and policy	7,519	12,968	6,640	57,169	5,492	89,788
Information and services	16,716	28,829	14,761	127,096	12,210	199,612
Research	1,036	1,786	915	7,875	756	12,368
	25,271	43,583	22,316	192,140	18,458	301,768
Fundraising	10,771	18,576	9,511	81,896	7,868	128,622
	36,042	62,159	31,827	274,036	26,326	430,390

6 Net movement in funds

	2020 (£)	2019 (£)
This is stated after charging:		
Operating lease	27,311	27,062
Depreciation of owned fixed assets	8,649	5,810
Auditor remuneration	6,250	6,250
Trustees' expenses	3,275	2,486
Pension costs	20,121	18,106

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

This does not cover any employees who are also Trustees in their capacity as Trustees and acting as such. The sum expended by the Charity on such insurance for the year to 31 March 2020 was £2,322 (in 2019 it was £1,866).

7 Staff costs and emoluments

	2020 (£)	2019 (£)
Gross salaries	585,545	558,282
Employer's National Insurance	51,107	50,662
Pension contributions	20,121	18,106
	656,773	627,050

Numbers of full-time employees or full-time equivalents

	2020	2019
Engaged on charitable activities	13	11
Engaged in fundraising activities	4	5
Engaged on management and administration	4	3
	21	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 £97,332 (£82,457 in 2019).

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

	2020 (£)	2019 (£)
The Trustees all give freely their time and expertise without any form of remuneration or other benefit in cash or kind.	–	–
Total expenses reimbursed to Trustees or met by the charity. These expenses were made up of five Trustees for travel and accommodation for the purpose of attending Board meetings.	3,275	2,486
Amounts of expenses incurred by Trustees that were donated back to the charity.	406	737
There were no related party transactions up to 31 March 2020.		

9 Tangible fixed assets

	Office equipment (£)
Cost	
At 1 April 2019	47,501
Additions for year	10,239
Disposals in year	2,965
At 31 March 2020	54,775
Depreciation	
At 1 April 2019	21,910
Charge for year	8,649
Disposals in year	2,965
At 31 March 2020	27,594
Net book value	
At 31 March 2019	25,591
At 31 March 2020	27,181

10 Debtors

	2020 (£)	2019 (£)
Trade debtors	120	284
Prepaid expenses	24,849	24,066
Due from HMRC	2,920	1,295
Accrued income	102,148	60,737
	130,037	86,382

11 Creditors: amounts falling due within one year

	2020 (£)	2019 (£)
Trade creditors	18,247	14,538
Deferred income	721	–
Accrued expenses	17,746	88,684
Unpaid pension contributions	3,451	3,032
Other taxation and social security costs	12,879	17,685
	53,044	123,930

12 Funds

	General funds (£)	Designated funds (£)	Total (£)
Statement of unrestricted funds			
Balance at 1 April 2019	363,744	–	363,744
Transfer between funds	(90,000)	90,000	–
Surplus for year	(54,099)	–	(54,099)
Balance at 31 March 2020	219,645	90,000	309,645

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

	Tangible fixed assets (£)	Cash	Other Net current liabilities (£)	Total (£)
Analysis of net assets between funds – prior year				
Unrestricted funds:				
General funds	25,591	375,701	(37,548)	363,744
Designated funds	–	–	–	–
	25,591	375,701	(37,548)	363,744
Restricted funds	–	198,688	–	198,688
	25,591	574,389	(37,548)	562,432

13 Restricted funds

	Opening balances £	Incoming resources £	Outgoing resources £	Closing Balances £
Movements in restricted funds				
Research	137,538	41,457	53,911	125,084
Scotland services	–	13,750	13,750	–
Children’s and Young People’s Service	–	70,279	43,295	26,984
Regional advocacy services	13,248	48,850	44,810	17,288
Mentor M.E.	45,109	63,703	66,709	42,103
M.E. Friends Online	2,793	10,000	12,793	–
Printed resources	–	4,878	–	4,878
Information and support	–	18,750	18,750	–
	198,688	271,667	254,018	216,337

Research – donations received from donors wishing to see advances in research. Two pilot research studies have been supported in part from this fund during the year. See the grant activities table on p 32 for more details.

Scotland services – funds from donors and trusts who asked that their donation be restricted for work in Scotland.

Children’s and Young People’s Service – donations for our work with children and young people (aged up to 19 years) living with M.E., and their families. The service includes support for complex cases and peer-support for young people and parents.

Regional advocacy – Throughout the South West and Midlands, this project aimed to develop a telephone and face-to-face advocacy service, enabled by 30 volunteers and two paid advocates. Since April 2020 we now offer advocacy UK-wide as part of our Crisis, Advocacy and Support Service.

Mentor M.E. – funded by Health and Social Care Alliance Scotland from the Transforming Self-Management in Scotland Fund. This project is developing a network of volunteer peer mentors supporting people living with M.E. in Scotland. We began recruiting volunteers in December 2016, and are matching mentors with mentees across Scotland for one-to-one support.

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

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

Information and support donations for our service offering one-to-one information support by phone and email for people with M.E. on a wide range of issues including symptom management and welfare benefits.

14 Pension commitments

The charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable to the scheme and is disclosed in note 7. Contributions in the sum of £3,451 (£3,022 in 2019) were outstanding at the balance sheet date.

15 Operating leases

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

	Total Leases 2020 (£)	Total Leases 2019 (£)
Operating lease payments falling due:		
within one year	26,917	26,719
within two to five years	1,710	26,538
over five years	–	–
	28,627	53,257

16 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.

17 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 £120,666 of which £30,666 is to be spent in the year to 31 March 2021.

18 Prior year restatements

Prior year restatements			
	At 1 April 2019 (£)	Adjusted amount (£)	Restated amount (£)
Total incoming resources	1,112,958	(36,503)	1,076,455
Total resources expended	1,277,457	(34,647)	1,242,810
Net movement in funds	(164,499)	(1,856)	(166,355)
Reconciliation of funds			
Accumulated funds at 31 March 2018	732,702	(3,915)	728,787
Accumulated funds at 31 March 2019	568,203	(5,771)	562,432
Cash at bank at 31 March 2019	580,160	(5,771)	574,389
Total assets less current liabilities at 31 March 2019	568,203	(5,771)	562,432

Legal and administrative details

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 2019 – 2020

President

Clare Francis MBE

Founding President

Sue Finlay

Vice President

Martin Arber

Patrons

Lord Bragg

Julie Christie

Lord Puttnam CBE

Alan Cook CBE

Honorary Patron

Ondine Upton (from March 2020)

Principal Medical Advisers

Dr Gregor Purdie

Prof Julia Newton

Board of Trustees

Roger Siddle, Chair (from February 2020)

Matt Symonds, Interim Chair
(October 2019 to February 2020)

Jonah Grunsell, Chair
(stood down October 2019)

Philip Marsden, Treasurer

Colin Batten

Gordon Berry (stood down October 2019)

Christopher Cundy

Alison Deeth

Andy Dougan

Lucy Goodwill (from October 2019)

Sue Hardy

Phil Murray

Jane Stacey

Ed Stephens

Jane Young

Chief Executive

Sonya Chowdhury



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