

Action for M.E. Trustees' report

2020 – 2021



Lifeline through lockdown...

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

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

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

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

While ensuring we support people now, we have continued to work to secure change for the future. In September 2020, we commenced work on the world's largest M.E. DNA study, DecodeME. With £3.2 million funding, we are co-leading this study with Prof Chris Ponting and

colleagues at the University of Edinburgh, people with M.E. and carers. The involvement of people with lived experience of M.E. has led to significant changes in the study's design and we are proud to be a part of this ambitious partnership. We need to recruit 20,000 people with M.E. in the UK, over the age of 16, who meet quite strict research criteria. With recruitment opening in autumn 2021, we have a lot to do and, with the help of the M.E. community, I am confident we will achieve this.

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

New strategy

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

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

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

- Providing services and lobbying for change cannot be done without funds. Donations, fundraising and other support that enables us to increase our networks of potential donors is critical. **Find out more at www.actionforme.org.uk/make-a-difference**
- Money is essential – but so is amplifying our voice and reaching people outside our current network. Sharing our content online, writing to your MP, MSP, AM or local media, or talking to other people about M.E. and its impact, all help raise awareness. **Join our Act4ME Network at www.actionforme.org.uk/Act4ME**
- We need your help in recruiting 20,000 people for the DecodeME study. Helping us reach this goal quickly means we can move one step closer to understanding more about the illness. Our aim is to enable development of targeted treatments and one day find a cure, so our vision of a world without M.E. becomes a reality. We do not know what the future holds but we are committed, as always, to working collaboratively, effectively and with determination to ensure that we are here when people need us. **Get involved at www.decode.me**

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



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

...Leader for change

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

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

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

As a direct result, we have been able to expand our support services,

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

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

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

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



Contents

Lifeline though lockdown... Leader for change	2
Reports from our Chief Executive and Chair of Board of Trustees	
Our year in numbers	5
Improving lives	6
People with M.E. get the information and support they need from us. We empower and advocate for young people, families and adults living with M.E.	
Inspiring action	8
We take action to remedy the ignorance, injustice and neglect still faced by people with M.E.	
Investing in change	10
We support people with M.E. to co-lead ground-breaking research	
How can we do more and do better over the next five years?	12
How we raised and spent our income this year	14
Financial review	15
Our people, structure and governance	17
Independent auditor's report to the Trustees and Members of Action for M.E.	19
Action for M.E. statement of financial activities	22
Balance sheet	23
Notes to the accounts	25
Legal and administrative details	36

On the cover (clockwise from top left):

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

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

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

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

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

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

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

Our year in numbers

1,754

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

80% increased understanding of their rights and options

78% increased their knowledge of support available



53

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

100% satisfaction with
the service received

91% reported
improved health
and wellbeing



168

families supported
through our services
for children and young people:

75% have increased understanding of their
rights and options

75% felt more confident communicating
with professionals

239,450

people found
information and support
on our website

10,300

downloads of our
booklets, factsheets
and support resources



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

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

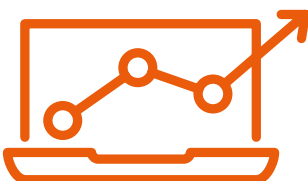
Feedback from clients:

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

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

31,308

sign ups to
DecodeME project
by March 2021



1,500

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



£169,710

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

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

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

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

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



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

1,754 times.

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



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

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

We work with everyone who gets in touch to:

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



239,450

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

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

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



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

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

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

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

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

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

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



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

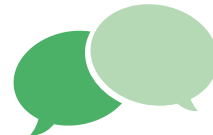
- **100%** said they were satisfied with the service received.
- **91%** reported improved health and wellbeing.
- **91%** improved self-advocacy skills.

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

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

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

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



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

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



What next?

We will:

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



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

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

Of the health professionals who completed the module:



• 100%
reported improvement in patient-centred care and patient pathways.



• 77%
reported increased confidence in treatment and management of M.E.



• 75%
reported increased confidence in diagnosis of M.E.

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

Dr Shaun Peter Qureshi, Edinburgh

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

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

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

We also:

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



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

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



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

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

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

We also:

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

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

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

"Action for M.E. has made me feel recognised and heard. The stories and research keep me optimistic and aware that I am not alone. I love the work they do."

Bethany (pictured), whose story we shared for M.E. Awareness Month



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



What next?

We will:

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

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

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

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

£3.2m

funding for DecodeME

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

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



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

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

"All of us involved with this research project hope that it can start to address the totally unwarranted stigma and lack of understanding that so many patients with ME/CFS face on a daily basis."



Register at www.decodeME.org.uk



Andy Devereux-Cooke,
ME patient and Co-Investigator

Your ideas could change the future of ME/CFS research.



To #PrioritiseME
visit www.psp-me.co.uk

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

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

Rachel Elliot, PSP Steering Group

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

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

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



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

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

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

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

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



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

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



£169,710 raised during Big Give



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



619 individual donations received



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

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

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

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

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



What next?

We will:

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

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

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

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

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

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

We will do more

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

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

Improving lives: health

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

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

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

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

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

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

Investing in change: research

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

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

Alongside delivering the world's largest DNA study through DecodeME, we are working collaboratively to progress the priorities identified by people with M.E. and clinicians through the Priority Setting Partnership (PSP) that we are currently funded to deliver.

We will continue to support the CMRC to secure increased funding for biomedical research while also seeking alternative ways to transform the research landscape.

We will invest in bringing new researchers into the field through PhD studentships and Fellowships.

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

Sian Leary, PSP Steering Group

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

Joan Crawford,
Counselling
Psychologist

Inspiring action: medical education

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

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

We will do better

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

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

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

How we raised and spent our income this year

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

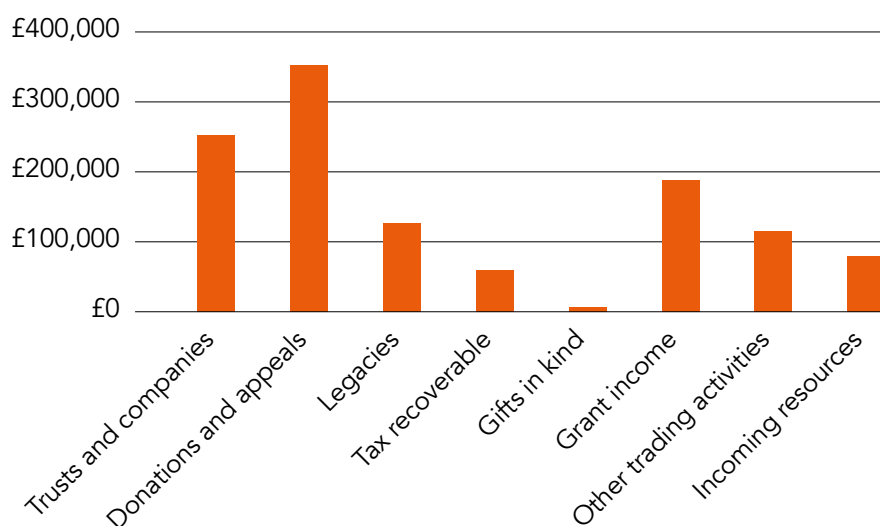
Our **recorded total income** (see bar chart below) for the year was £1,192,197, up 26% from the previous year. This is largely due to a record-breaking Christmas Big Give Challenge, increased success with trust applications and a number of legacies received during the year.

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



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

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



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

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

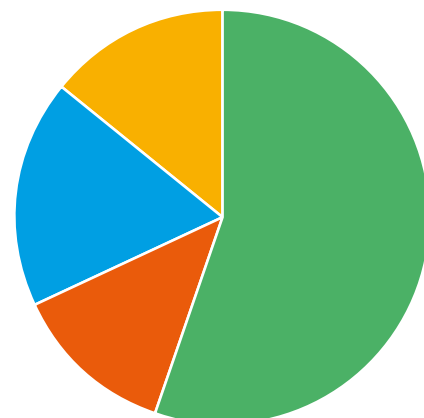
This year, we spent:

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

£106,296 on our campaigning and influencing work.

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

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



To carry out all our activities effectively, we need committed and dedicated staff who bring the right skills, knowledge and experience to every area of our work. That's why almost three quarters (73%) of our total gross expenditure is on staff salaries (including employer National Insurance and pension contributions).

Financial review

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

Thankfully, due to a phenomenal fundraising effort by our staff team and ongoing support from the M.E. community, we have seen our income increase by 26% compared to the previous year, achieving well over £1million in income together with a sound underlying financial performance, ending the year with a surplus of £359,533. We increased our digital fundraising activities and re-focused our trust fundraising work to make up for the predicted shortfall in community fundraising income. There are no contingent assets to report for the financial year 2020 – 2021. During the year the charity has been advised of a number of legacies and has received significant legacy income. The value of some legacies that are dependent on the sale of an estate could not be estimated within the accounting period and will be

recognised as income in the financial year they become certain.

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

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

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

Balance sheet

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

Funding sources

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

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

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

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



HM Government

In partnership with

THE NATIONAL LOTTERY
COMMUNITY FUND

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

Pears
Foundation

Financial review

Investment policy

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

Reserves policy

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

Grant-making policy

This policy sets the criteria and rules for making grants. This is reviewed annually and grants are restricted to the funding of medical research.

Statement of Trustees' responsibilities

The Trustees are responsible for preparing the Trustees' annual report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice). Company and charity law requires the Trustees to prepare financial statements for each financial year.

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

In preparing those financial statements the Trustees are required to:

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

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

They are also responsible for safeguarding the assets of the charity and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities. The Trustees are responsible for the maintenance and integrity of the corporate and financial information included on the charity's website, the Online M.E. Centre.

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

Auditor

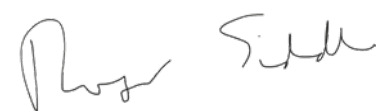
Moore (previously known as Moore-Stephens) was re-appointed as our auditor at the 2020 Annual General Meeting.

Provision of information to Auditor

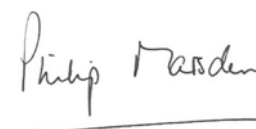
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish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

Small company provisions

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



Roger Siddle
Chair of Board of Trustees
and Directors



Philip Marsden
Director and Treasurer

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

Our people, structure and governance

Public benefit

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. The annual report contains a fuller description of the public benefit that the charity provides on pages 2 to 14.

Trustees

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

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

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

Our committees

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

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

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

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

Supporting Members vote on new appointments and the re-election of existing Trustees, with results subsequently confirmed at our Annual General Meeting (held this year in October 2020). Each new Trustee receives a full induction and has the opportunity to be paired with a 'buddy' for the first year on the Board, plus access to ongoing training.

Chief Executive

The Chief Executive is responsible for setting the strategic direction for the charity with the Trustees, leading its implementation, and holds delegated financial authority within parameters set out by our financial controls.

Collaborative partners

By working collaboratively with others who share our values, we can be more effective in achieving our aims and improving the lives of children, young people and adults with M.E. This includes other M.E. charities and patient organisations, health, social care and education professionals, government and senior officials, and other decision-makers. As a member of a number of organisations and alliances, including Forward M.E., Advice Centres for Avon, Disability Rights UK, Health Conditions in Schools Alliance and the Disability Benefits Consortium, we continue to build capacity, reach more people, and achieve more by working in partnership to achieve common goals.

Our people, structure and governance

We also provide secretariat support to the UK CFS/M.E. Research Collaborative, which led to the establishment of the M.E./CFS Biomedical Partnership, the group leading DecodeME (see p10).

Governing document

The organisation is a charitable company limited by guarantee and is a registered charity in England and Wales, and in Scotland, with further details provided on p 35. The Company was established under a Memorandum of Association which established the objects and powers of the charitable company and is governed under its Articles of Association. In the event of the Company being wound up members are required to contribute an amount not exceeding £1.

Fundraising policy

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

The charity recognises the need to conduct its fundraising within the context of recognised standards set out in the Institute of Fundraising's Code of Fundraising Practice, the Data Protection Act 1998/UKGDPR2021 and the CAP Code (Committee of Advertising Practice). We do not employ external professional fundraisers or companies.

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

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

Risk

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

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

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



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

Opinion

We have audited the financial statements of Action for M.E. (the 'charitable company') for the year ended 31 March 2021 which comprise statement of financial activities, the balance sheet, the cash flow statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including FRS 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland" (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2021 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are

relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

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

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial

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

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

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

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

Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' report. We have nothing to report in respect of the following matters where the Companies Act 2006, the Charities Act 2011 and the Charities Accounts (Scotland) Regulations 2006 (as amended) require us to report to you if, in our opinion:

- adequate and sufficient accounting records have not been kept, or returns adequate for our audit have not been received from branches

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

Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities Statement set out on page 16, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the Trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic

decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

Explanation as to what extent the audit was considered capable of detecting irregularities, including fraud

The objectives of our audit in respect of fraud, are; to identify and assess the risks of material misstatement of the financial statements due to fraud; to obtain sufficient appropriate audit evidence regarding the assessed risks of material misstatement due to fraud, through designing and implementing appropriate responses to those assessed risks; and to respond appropriately to instances of fraud or suspected fraud identified during the audit. However, the primary responsibility for the prevention and detection of fraud rests with both management and those charged with governance of the charitable company.

Our approach was as follows:

- We obtained an understanding of the legal and regulatory requirements applicable to the charitable company and considered that the most significant are the Companies Act 2006, UK financial reporting standards as issued by the Financial Reporting Council, and the Charities Act 2011.
- We obtained an understanding of how the charitable company complies with these requirements by discussions with management and those charged with governance.
- We assessed the risk of material misstatement of the financial statements, including the risk of material misstatement due to fraud and how it might occur, by holding discussions with management and those charged with governance.
- We inquired of management and

those charged with governance as to any known instances of non-compliance or suspected non-compliance with laws and regulations.

- Based on this understanding, we designed specific appropriate audit procedures to identify instances of non-compliance with laws and regulations. This included making enquiries of management and those charged with governance and obtaining additional corroborative evidence as required.

As part of an audit in accordance with ISAs (UK) we exercise professional judgement and maintain professional scepticism throughout the audit. We also:

- Identify and assess the risks of material misstatement of the financial statements, whether due to fraud or error, design and perform audit procedures responsive to those risks, and obtain audit evidence that is sufficient and appropriate to provide a basis for our opinion. The risk of not detecting a material misstatement resulting from fraud is higher than for one resulting from error, as fraud may involve collusion, forgery, intentional omissions, misrepresentations, or the override of internal control.
- Obtain an understanding of internal control relevant to the audit in order to design audit procedures that are appropriate in the circumstances, but not for the purposes of expressing an opinion on the effectiveness of the charitable company's internal control.
- Evaluate the appropriateness of accounting policies used and the reasonableness of accounting estimates and related disclosures made by the Trustees.
- Conclude on the appropriateness of the Trustees' use of the going concern basis of accounting and, based on the audit evidence obtained, whether a material uncertainty exists related to events or conditions that may cast significant doubt on the charitable company's ability to continue as a going concern. If we conclude that a material uncertainty exists, we are required to draw attention in our auditor's report to the related

disclosures in the financial statements or, if such disclosures are inadequate, to modify our opinion. Our conclusions are based on the audit evidence obtained up to the date of our auditor's report. However, future events or conditions may cause the charitable company to cease to continue as a going concern.

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

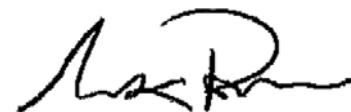
We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Councils website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's Trustees, as a body, in accordance with Chapter 3 of Part 8 of the Charities Act 2011 and regulations made under section 154 of that Act, and in accordance with Section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and regulations made under section 44 of that Act. Our audit work has been undertaken so that we might state to the charitable company's members and the charity's Trustees those matters we are required to state to them in an

auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company, the charitable company's members as a body, and its Trustees as a body, for our audit work, for this report, or for the opinions we have formed.



Mark Powell, Senior Statutory Auditor
For and on behalf of Moore,
Statutory Auditor

Moore is eligible to act as an auditor in terms of section 1212 of the Companies Act 2006

Bath, UK
24 September 2021

Action for M.E. statement of financial activities

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

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

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

Balance sheet

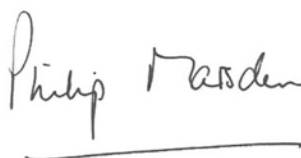
As at 31 March 2021 (company registered number 2906840)

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

The accounts have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 and in accordance with Financial Reporting Standard 102 and the Charities SORP (FRS 102). The notes on p 24 to 34 form an integral part of these accounts.



Roger Siddle
Chair of Board of Trustees and Directors



Philip Marsden
Treasurer

Approved by the Board of Trustees 31 August 2021

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

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

Notes to the cash flow statement

a Cash flows from operating activities

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

b Cash flows from investing activities

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

Analysis of changes in Net Funds

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

Notes to the accounts

1 Accounting policies

The financial statements have been prepared in accordance with Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2019) as updated by Bulletin 1 – ('Charities SORP (FRS 102)'), the Financial Reporting Standard applicable in the UK and Republic of Ireland ('FRS 102') and the Companies Act 2006.

Action for M.E. is a private company limited by guarantee and registered in England and Wales. Its registration details are given on p 34. It meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s). The financial statements are prepared on a going concern basis. The Trustees consider that there are no material uncertainties over going concern. The preparation of financial statements in compliance with FRS 102 Section 1A Small Entities requires the use of certain critical accounting estimates. It also requires management to exercise judgement in applying the accounting policies.

Fund accounting

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

Deferred income

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

Recognition of liabilities

Liabilities are recognised on the accruals basis.

Investments

Investments are valued at mid-market value at the year-end. Realised and unrealised gains or losses are credited or charged to the relevant fund in the Statement of Financial Activities.

Incoming resources

Incoming resources, including bank interest receivable, are accounted for on a receivable basis when the Charity is legally entitled to the income and the amount can be quantified with reasonable accuracy.

Donated services and facilities are included as voluntary income at their estimated value to the Charity when received, and under the appropriate expenditure heading depending on the nature of the service or facility provided. Time donated by volunteers is not recognised in the financial statements as this cannot be reliably valued. For Legacies, entitlement to funds, the measurable amount of the legacy and the probability that it will be received inform the decisions around recognition and receipt of legacy funds. Deferred income, where appropriate, is accounted for as above.

Resources expended

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to that category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Support costs are allocated to operational and fundraising functions on the basis of their use of central support services.

Grants payable are payments made to third parties in furtherance of the Charity's objectives. Single or multi-year grants are accounted for when either the recipient has a reasonable expectation that they will receive a grant and the Trustees have agreed to pay the grant without condition, or when the recipient has a reasonable expectation that they will receive a grant and any condition attaching to the grant is outside the control of the Charity. Where a grant includes specific performance terms, grants payable are recognised as performance milestones are met.

Provisions for grants are made when the intention to make a grant has been communicated to the recipient but there is uncertainty about either the timing or the amount of the grant.

Fundraising costs are those incurred in seeking voluntary contributions and do not include the costs of disseminating information in support of the charitable activities.

Charitable expenditure comprises those costs incurred by the Charity in the delivery of its activities and services for its beneficiaries. It includes both costs that can be allocated directly to such activities and those costs of an indirect nature necessary to support them.

Support costs include all expenditure not directly related to charitable activity. The Trustees have applied what they consider to be reasonable judgements in apportioning such costs between direct charitable costs

and support costs. The central office functions such as general management, payroll administration, budgeting and accounting, information technology, human resources and financing, are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of the cost allocation is explained in note 5 to the accounts.

Governance costs are the costs associated with the governance arrangements of the Charity which relate to the general running of the Charity as opposed to those costs associated with fundraising or charitable activity. Included within this category are the cost of audit fees and costs linked to the strategic management of the Charity.

Governance costs are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of allocation is explained in note 5 to the accounts.

Fixed assets and depreciation

Tangible fixed assets are stated at cost less depreciation. Items of less than £500 are not capitalised. Depreciation has been provided at the following rates in order to write off the cost of the assets (less their expected residual value) over their estimated useful economic lives. Office Equipment – 25% on the straight line method.

Pensions

The Charity operates an occupational pension scheme. Contributions are charged to the Statement of Financial Activities as they become payable in accordance with the rules of the scheme. The scheme is a defined contribution scheme.

Taxation

As a registered Charity whose income and gains are used solely for its charitable purposes, the Charity falls within the exemption for corporation tax and as such has had no tax charge for this accounting period. The Charity operates a partial-exemption method for the recovery of certain VAT. The amount of VAT that cannot be recovered is included in support costs and is £18,566 (£24,008 in 2020).

Operating lease agreements

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

Financial instruments

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

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

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

- Apportionment of staff time on specific activities has been made in the absence of formal timesheets and therefore based on the role profiles and work-plans of the individuals, as in previous years.
- A Gift in Kind valuation of the pro-bono legal work undertaken by Allen & Overy for small projects has an agreed 'in kind value' of £1,000.
- A further gift in kind value of £900 has been recorded for podcast work undertaken for a project in Scotland and an amount of £1,300 towards other legal services.
- The valuation and recognition of pending legacies throughout the year and specifically at the year-end is based on the charity's entitlement to funds, the availability of sufficiently reliable estimates of the amount indicated for the legacy and the probability that it will be received.

3 Details of incoming resources

	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Donations and legacies				
Trusts and companies	104,406	149,422	253,828	263,261
Donations and appeals	326,027	27,395	353,422	317,675
Legacies	114,042	13,882	127,924	130,995
Tax recoverable	63,360	4,039	67,399	57,551
Gifts in kind	3,200	–	3,200	5,493
Grant Income	10,000	183,333	193,333	63,703
	621,035	378,071	999,106	828,678
Other trading activities				
Lotteries and raffles	11,889	–	11,889	9,743
Christmas cards	2,602	–	2,602	3,653
Supplement commission	2,588	–	2,588	1,688
Merchandise	163	141	304	965
Events	–	–	–	750
Other	18,315	75,622	93,937	17,976
	35,557	75,763	111,320	34,775
Incoming resources from charitable activities				
Subscriptions	81,377	–	81,377	82,906
Charity journal	–	–	–	1,568
Information and publications	23	–	23	332
	81,400	–	81,400	84,806

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

4 Investment income

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

5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Costs of generating voluntary income				
Staff costs	13,965	–	13,965	28,420
Direct fundraising costs	11,102	–	11,102	13,968
Support costs – see below	83,782	6,000	89,782	95,082
	108,849	6,000	114,849	137,470
	Unrestricted funds (£)	Restricted funds (£)	Total 2021 (£)	Total 2020 (£)
Charitable activities				
Information and support services	193,908	268,288	462,196	489,961
Campaigning and influencing work	103,329	2,967	106,296	289,795
Collaborative biomedical research	32,856	115,437	148,293	65,230
	330,093	386,692	716,785	844,986

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

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

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

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

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

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

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

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

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

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

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

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

6 Net movement in funds

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

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

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

7 Staff costs and emoluments

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

Numbers of full-time employees or full-time equivalents

	2021	2020
Engaged on charitable activities	11	13
Engaged in fundraising activities	4	4
Engaged on management and administration	4	4
	19	21
The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:		
	Number	Number
	1	1

The Charity considers its key personnel to comprise the Trustees and the Chief Executive Officer. The total employment benefits including employer pension contributions of the key personnel were £87,391 (£87,391 in 2020).

The Charity remains grateful for the work of its volunteers. The role and scope of work undertaken varies, and takes into account the fluctuating energy levels of the volunteers, many of whom are affected by M.E.

The time donated by volunteers is not recognised in the financial statements as this cannot be reliably or consistently valued.

8 Trustees

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.

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

There were no related party transactions up to 31 March 2020.

2021 (£)	2020 (£)
–	–
–	3,275
–	406

9 Tangible fixed assets

Office equipment (£)

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

10 Investments

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

There were no investment assets outside of the UK.

11 Debtors

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

12 Creditors: amounts falling due within one year

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

13 Funds

	General funds (£)	Designated funds (£)	Total (£)	
Statement of unrestricted funds				
Balance at 1 April 2020	219,645	90,000	309,645	
Transfer between funds	(250,000)	250,000	–	
Surplus for year	298,405	–	298,405	
Balance at 31 March 2021	268,050	340,000	608,050	
	Tangible fixed assets (£)	Cash	Other Net current assets (£)	Total (£)
Analysis of net assets between funds – current year				
Unrestricted funds:				
General funds	27,679	137,344	103,027	268,050
Designated funds	–	340,000	–	340,000
	27,679	477,344	103,027	608,050
Restricted funds	–	211,911	65,554	277,465
	27,679	689,255	168,581	885,515

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

14 Restricted funds

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

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

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

DecodeME – funding awarded jointly by the Medical Research Council and National Institute for Health Research for our role in co-leading this research project as part of the ME/CFS Biomedical Partnership.

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

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

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

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

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

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

15 Pension commitments

The Charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable to the scheme and is disclosed in note 7. Contributions in the sum of £3,482 (£3,451 in 2020) were outstanding at the balance sheet date.

16 Operating leases

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

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

17 Contingent assets

During the year the Charity has been advised of a number of legacies and has received significant income. The value of some legacies that are dependent on the sale of an estate could not be estimated within the accounting period and will be recognised as income in the financial year they become certain.

18 Research funding commitments

The Charity is committed to funding a number of research grants over the forthcoming years subject to certain performance conditions being met. The Charity is committed to further expenditure of £105,000 of which £75,000 is to be spent in the year to 31 March 2022.

Legal and administrative details

Action for M.E.

Registered charity No 1036419
Registered in Scotland SC040452
Incorporated on 10 March 1994
Company registration number 2906840

Registered office
42 Temple Street
Keynsham
Bristol BS31 1EH

Bankers

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

Auditor

Moore
30 Gay Street
Bath BA1 2PA

Trustees and Directors 2020 – 2021

President

Clare Francis MBE

Founding President

Sue Finlay

Vice President

Martin Arber

Patrons

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

Honorary Patron

On dine Upton

Board of Trustees

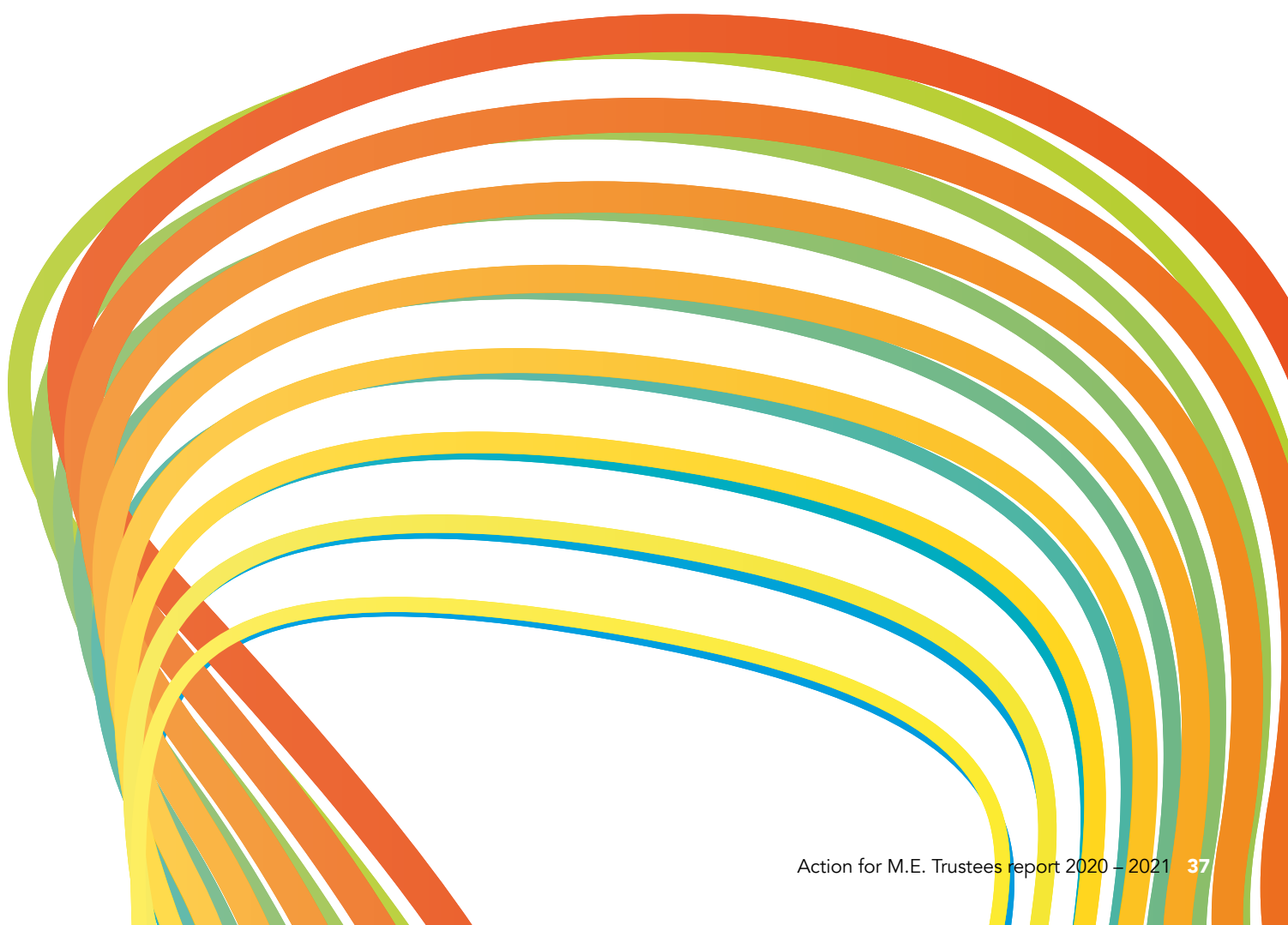
Roger Siddle, Chair
Philip Marsden, Treasurer
Matt Symonds
Colin Batten
Christopher Cundy
(stood down October 2020)
Shaun De Boo
(joined February 2021)
Alison Deeth
Andy Dougan
(stood down October 2020)
Lucy Goodwill
Sue Hardy
David Leigh
(joined December 2020)
Jonathan Manuel
(joined March 2021)
Phil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

Chief Executive

Sonya Chowdhury

Principal Medical Advisers

Dr Gregor Purdie
Prof Julia Newton



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

Action for M.E. supporter



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

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