



# Improving lives, inspiring change

Trustees' report  
2017 – 2018



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On the cover: Oliver, 12, was a keen fell runner and captain of his local football team before he became ill with M.E. His mum Catherine says: "Having support from Action for M.E. means a lot. Oliver got a card from them on his birthday, and it made a big difference to receive something from people who understand how it feels to have M.E."

# Taegan, 15, has M.E.

"I don't think anyone really understands what M.E. is and how it affects me – in fact, I don't even get it. The toughest thing is not being able to do any social things like I used to, and when I do see my friends I have to limit the time we spend together. When we meet, it always has to be at my house as I am not always well enough to go out."

Her mum Samantha says: "Before M.E., I had a daughter who was a high-achieving gymnast, cheerleader and dancer who was looking forward to a career in dance. She loved going out with her friends and would never miss a day from school. She had many hopes and dreams for the future."

"At the moment we are just about managing a routine that means she is no longer sleeping 22 hours a day. It's like her life has just stopped: she is not learning, making new friends,

or having new experiences. She is just at home trying to make the best of the time she is awake and finding things she can manage, like drawing or listening to music and stories.

"Action for M.E.'s website was amazing when we were first diagnosed. We printed out some of the information for her school and teachers, plus we asked our close friends and family to have a look so that they could read it for themselves. The support on the phone has been very positive. Although just a small team they all work really hard to help."

"I had a call from their Head of Children's Services who was able to help us through a very difficult time when the school and council were questioning her attendance".



*"We would not have come through this without Action for M.E."*

- Myalgic Encephalomyelitis (M.E.) is a serious chronic condition that affects 250,000 people in the UK – more than MS and Parkinson's disease combined.
- One in four people with M.E. is so severely ill all the time that they are house- and/or bed-bound, unable to manage even basic self-care.<sup>3</sup>
- It's more common in women than in men, and affects children and young people, too: it is the most common cause of long-term absence among school children.<sup>1</sup>
- M.E. costs the UK economy at least £3.3 billion per year, including healthcare costs, disability-related welfare payments, productivity losses and unpaid informal care.<sup>4</sup>
- There's a common misconception that M.E. is just "feeling tired" – but it's so much more than that, with symptoms that affect most bodily systems. People with M.E. score lower overall on health-related quality of life tests than most other chronic conditions – including prostate cancer, breast cancer, rheumatoid arthritis and schizophrenia.<sup>2</sup>
- Yet research into M.E. represents less than 1% of all active grants given by UK mainstream funding agencies. Accelerated biomedical research is urgently needed to understand the biology of this debilitating condition<sup>5</sup>.

*See page 35 for references*

# Speaking louder and with one voice

I am pleased and proud to report that this year has seen us reach more people than last year – and the year before. The extent of this increase has been most pronounced online, with a 148% increase in visits to our Online M.E. Centre in 2017–2018, compared to the previous 12 months. That means more children, young people and adults with M.E. are coming to us to find information and advice on key issues affecting them and their family. We've widened our net geographically, too, leading on the first ever M.E.-focused side event at the World Health Assembly in Geneva in May (just after year-end), as part of our international advocacy work, aimed at influencing national policy.

Our most significant news this year was the launch of our new Children and Young People's Service. We

merged with UK charity, the Association of Young People with M.E., in April 2017 because we believed that, by working together, we could reach more young people like Taegan, whose story you read on p 3.

Adding to the promises we already made to adults living with M.E., we revised our 2016 – 2021 strategy, based on the views, experiences and ideas of more than 400 young people, parents and professionals, who told us what they need and want from us, led by a group of their peers.

You can read about the progress of this revised strategy on the following pages, and hear from some of those people about the difference our work has made for them – and about how we will build on this in the year to come.

None of this would have been possible without the generous support of the trusts, foundations, individual donors, Supporting Members and fundraisers whose invaluable contributions ensure we are here for people with M.E. when they need us. To all of them, on behalf of my team, our Board of Trustees, and everyone we support, I say thank you.



Sonya Chowdhury  
Chief Executive

One of the phone calls I was most pleased to receive this year was from Sonya, telling me that the target we set for our week-long Big Give Christmas Challenge campaign had already been reached – on the second day. This was our first year taking part, and it was fantastic to see this level of enthusiasm from people wanting to support the charity.

I was incredibly moved to see so many £5 donations from our Supporting Members, many of whom are unable to give more, and who describe our services as a "lifeline." Thanks to the support of our match-funder, Candis and other philanthropists, donations from £5 to £5,000 were doubled, helping us raise more than £121,000 in a single week.

The success of our Big Give Christmas Challenge – which we aspire to match in 2018 – has contributed to our strong financial performance this year for the third year running, along with two legacies totalling £203,496.

Our recorded total income was £1,268,718, and overall expenditure was up 41%, reflecting our critical investment in vital services and initiatives including the launch of our Children and Young People's Service, our international advocacy work, and increased overall investment in income generation.

I would like to join Sonya in extending my grateful thanks to the Board of Trustees, the staff team, our volunteers and everyone who supports our work. This includes not

only the trusts, foundations, individual donors, Supporting Members and fundraisers, but also our online supporters and media case studies, for the time and energy you so willingly spend on raising awareness of our work, and of M.E. and its impact. Thank you.



Jonah Grunsell  
Chair, Board of Trustees

# Progressing our strategy

Action for M.E. was established in 1987 for the relief of people with M.E., to provide information, advice and support, and to promote public education, campaigning and research into the disease. In the past three decades, we have seen some progress but there is still much to do. In July 2016, we launched a five-year strategy for change. We want to improve the lives of people with M.E., inspire action at all levels, and invest in change. We can only do this by working with others who share **our values of empathy, clarity, courage and collaboration**, making the most of all the resources at our disposal. These can seem dwarfed by the scale of the challenge – but by working collaboratively and creatively, we have been able to make progress.

## Improving lives

People with M.E. need reliable information that they can access at the time they need it, to make informed decisions about their care. Over five years, we promised to achieve a 20% increase in the number of times our Information and Support Officers, and our specialist Welfare Advisors, gave one-to-one support. **This year, our Information and Support and Welfare Advice services responded to 24% more calls and emails than the year before, from young people, adults and families living with M.E.**

Read more about the outcomes of our IMPROVE work on p 6.

## Inspiring action

People with M.E. want to see M.E. taken seriously by the professionals and policy-makers who make decisions that affect their lives. We promised to explore how advocating for people with M.E. at World Health Organization level could result in policy changes that improve lives in the UK. **We now lead an international alliance of patient organisations committed to influencing international decisions that affect national policies on M.E. in the UK and across the world, highlighting the need for meaningful consultation with people with M.E.**

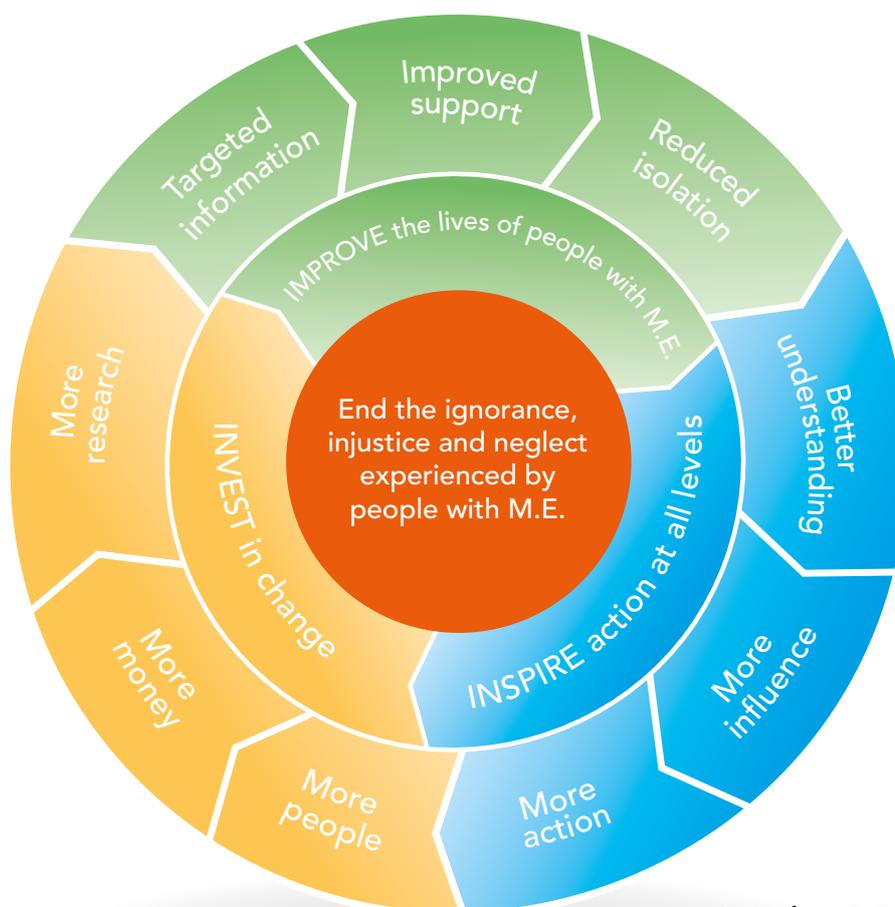
Read more about the outcomes of our INSPIRE work on p 8.

## Investing in change

People with M.E. want to see biomedical research that leads to improvements in treatments in symptom management, and ultimately a cure. We promised to invest in pilot research projects and bring new researchers to the field.

**Following our funding calls in October and February, two new PhD studentships in biomedical M.E. research, totalling £182,000 (awarded after year-end), are being taken forward at the University of Edinburgh and Brighton and Sussex Medical School.**

Read more about the outcomes of our INVEST work on p 10.



# We support people with M.E. to make informed decisions and feel less isolated

Thanks to the generous support of trusts and individuals, we have been able to extend our reach to more people looking for information, advice and peer-support.

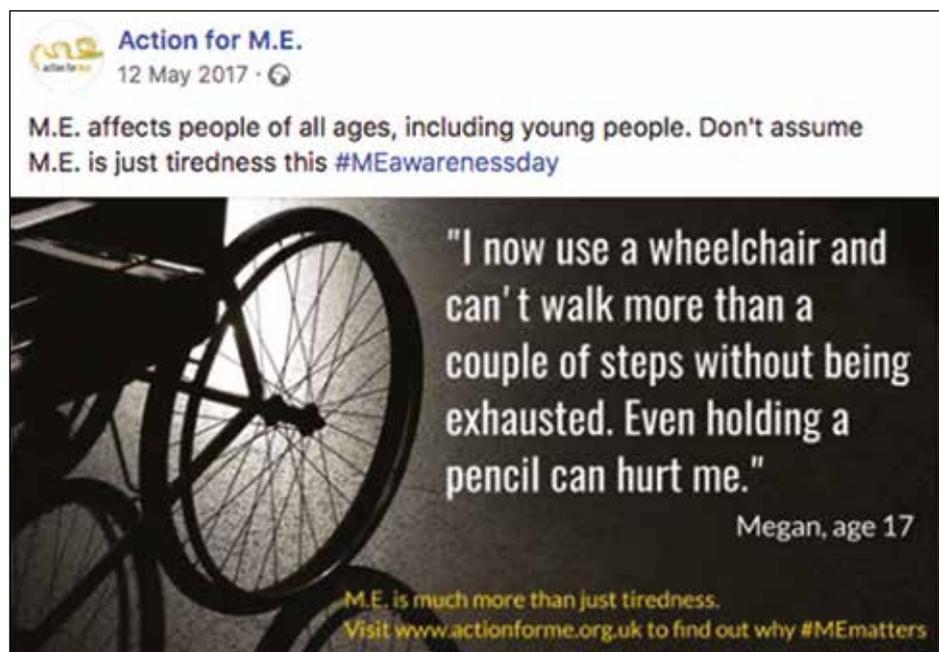
More than 1.9 million people saw content from, or about, Action for M.E. in their Facebook feed this year. For those who don't know anything about M.E., it's a chance to learn and understand a little more about the condition and its impact. For young people and adults living with M.E. every day, it's a much-needed reminder that they are not alone.

Getting the right information at the time they need it most can also make a genuine and lasting difference. Our Information and Support Service provided one-to-one information, advice or support more than 1,150 times to people of all ages facing the challenge of living with M.E. – and hundreds of thousands more found support in our Online M.E. Centre, most of them (86%) for the first time.

We are thrilled that our peer mentoring project, Mentor M.E. won Most Promising Disability & Health Project at the 2017 Scottish Mentoring Network Recognition awards.

*"I signed up to be a mentee and have found the support I have received to be invaluable. I would encourage you to sign up and offer your time. To somebody in those initial stages of diagnosis, or at any time, we all need somebody to help us with this illness. This is a brilliant project."*

Liza Bowlzer, one of our Mentor M.E. volunteers.



**Action for M.E.**  
12 May 2017 · 🌐

M.E. affects people of all ages, including young people. Don't assume M.E. is just tiredness this #MEawarenessday

*"I now use a wheelchair and can't walk more than a couple of steps without being exhausted. Even holding a pencil can hurt me."*  
Megan, age 17

M.E. is much more than just tiredness.  
Visit [www.actionforme.org.uk](http://www.actionforme.org.uk) to find out why #MEMatters

Comment from Megan's mum Jo on this Facebook post: "I just wanted to say thank you so much for all of the likes and shares you have given it. As you know it's M.E. Awareness Week, and all week I have been posting, asking people to show their support for me and Megan. Not one person did. I have had just two likes on this quote on my Facebook page. To be honest it's really disappointing and hurtful, not only for me but for Megan, too. When this quote was posted [by Action for M.E.] she couldn't believe the response it was having. It made her day, her week! You don't realise how much this has meant to us. Thanks again."



*"I found so much helpful information that I was able to print off that was instrumental in me getting diagnosed, understanding the condition, and how to explain that to those I cared about. So I am very grateful for that. I still struggle a lot but, compared to where I was a few years ago, bedridden and mostly homebound, I have come a long way with just better understanding. It means a lot to me to try and support others going through the same."*

Action for M.E. fundraiser, Chloe Langton, pictured with husband, Adam

People living with M.E. contacted our Welfare Advice and Support Service **more than 860 times**, with

**99.7% saying they felt better informed**

about their rights and entitlements.



**More than 1,150 people visited our Online M.E. Centre every day** on average – a

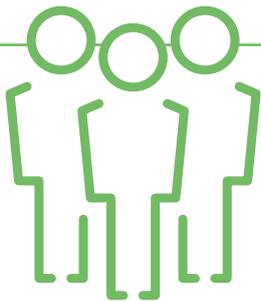
**148% increase**

in visits compared to the previous year – to find information and advice on key issues affecting them and their family.

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“Many thanks to you all for the very important work you do. **I always look forward to *InterAction* dropping through my letterbox and identifying with the comments and struggles of others.** Your updates on research and welfare benefits are always a help, too. You are all so important to us and we are so grateful for everything that you do on an ongoing basis. Your efforts are not forgotten.” **Elsbeth, by letter**

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More than **2,780** children, young people and adults are registered to use **our three peer-support forums.**

We held our **first welfare benefits seminar.** “Your advisor was so informative and helpful. She answered all my questions and offered to help me with my PIP claim.

**It has given me a boost of confidence and massive motivation to start to fill my forms in.**

Thank you!” **Jade, who attended our seminar**



Essential welfare benefits factsheets, our booklet for those newly diagnosed, and other information and support **resources were downloaded nearly**

**20 times every hour.**

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“Action for M.E arranged for me, my mum and brother to attend a Christmas party at 10 Downing Street, which is the first time I met others with the same condition, and we had a great time. **It was a good feeling to know I am not alone** and not to feel sorry for myself as there are others who have to deal with more severe cases of M.E.” **Ethan, 13 years old**

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# We increase knowledge among professionals, policy-makers and the public

Working to change the policies that have a direct impact on the lives of people with M.E. requires determination and persistence – and this year it paid off. The M.E. community was united in cautious celebration in September when National Institute for Health and Care Excellence (NICE) announced a full review of its clinical guideline on M.E. for England and Wales, following extensive submissions from charities and advocates, including Action for M.E.

Over the next two years, we will work with NICE to ensure that people with lived experience of M.E. play a central role in developing new guidance, and that the guidance itself equips health professionals with everything they need to offer their patients appropriate care and support.

## File on Four

Thanks to national media coverage of our shocking survey, featured on BBC's *File on Four*, millions of people had the opportunity to hear from families falsely accused of making their children with M.E. deliberately ill, and understand the devastating impact on parents and young people already under huge pressure.

Working with *Special Educational Needs* magazine, we also shared our findings with teachers, SENCOs, carers, parents, therapists and special needs practitioners – and shared key knowledge on how they can better support these vulnerable families.



## Advocating for change

We know that real change for people with M.E. in the UK is only possible if their needs are addressed by decision-makers at every level – local, national and international. In January we announced our plans to explore how advocating for people with M.E. at World Health Organisation (WHO) level could result in policy change that improve lives in the UK.

Our aim is that, over the next few years, the WHO and its Member States – including the UK – consult with people affected by M.E., in a transparent and meaningful way, to lead a global public health response to this illness, through the adoption of a formal resolution at the World Health Assembly (the WHO's supreme decision-making body). We want to see this include accelerated biomedical research, and appropriate medical education for professionals working with people with M.E.

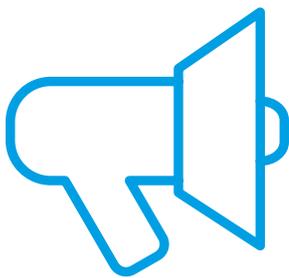
We were able to put this ambitious plan in place thanks to a generous legacy, received in August. Sonya Chowdhury, our Chief Executive, says, "It's a big step for the charity, and our Board of Trustees has carefully considered this significant investment, which will be regularly reviewed to ensure it delivers benefit for people with M.E."

We also lead a collaborative group, the International Alliance for M.E. (IAFME), with representation from the US, Australia, Spain, New Zealand, South Africa, Japan, Wales and the UK. Just after year-end, the IAFME, led by Action for M.E. and hosted by the Union for International Cancer Control, held the first ever M.E.-focused side event at the World Health Assembly in Geneva. As part of the global Millions Missing campaign on 12 May, we shared stories from people with M.E. in an event outside the UN headquarters, with scores of empty shoes (pictured) representing the lives stolen by M.E.

We highlighted the urgent needs of children and adults with M.E., and the difference good practice and appropriate services can make, in our responses to

## 10 government consultations

on welfare benefits, healthcare, transport, employment and education in England, Wales, Scotland and Northern Ireland.



We developed

### six new resources

for healthcare professionals:

- four webinars, shared with **more than 250 GPs and other health professionals**, and led by a range of professionals including pharmacist and Action for M.E. volunteer, Emily Beardall
- two professional briefings, for **OTs and physiotherapists**
- our 20-page toolkit for pharmacists on how best to support people with M.E., shared with more than **10,000 pharmacy professionals** and policymakers.

Our letters, stories, interviews and case studies were shared by nearly

## 400 digital, print and broadcast outlets,

including *BBC Radio 4, Mail Online, Huffington Post, ITV, The Daily Telegraph, The Scotsman, South Wales Argus* and Belfast's *NVTV*. Paying for this level of coverage would have cost **almost £1.2m, equal to our total recorded income.**

As part of the Medical Conditions in Schools Alliance's Safe in Schools, we met with MPs and delivered a petition

## signed by 50,000 people

asking the Department of Education to do more to keep children with medical conditions safe in school, including implementing existing legislation.



This year, we have given

## specialist, one-to-one support to 230 families

facing complex and difficult challenges.



"When Mary-Jane [Action for M.E.'s Head of Children and Young People's Services] got involved we were, after two years of fighting, able to get funding for my son to see a CFS/M.E. specialist. **Prior to this I was being accused of Fabricated or Induced Illness (FII) because no one believed in M.E.** Now my son's health is improving. Without Mary-Jane's input I think he would have been bedbound by now, instead of looking forward to starting senior school part-time." **Parent of 11-year old boy with M.E.**



# We drive new collaborations to increase interest and investment in research

As a Board member and key player in the UK CFS/M.E. Research Collaborative (CMRC), Action for M.E. takes a proactive role in driving new collaborations to increase interest and investment in research. More than 80 researchers, clinicians and patients came together at the 2017 CMRC conference in September (pictured), organised by Action for M.E. to hear from international scientists leading the way in M.E. research.

In March, the Board of the CMRC announced its intention to adopt biomedical M.E. research as its core focus. As part of the Board, we will:

- build on the momentum created by the Institute of Medicine in the US by securing a high-level report on the illness and research in the UK, and use this to seek greater investment from policy and decision-makers
- secure a James Lind Alliance Priority Setting Partnership to shape the research priorities for the field, which will have patients' views at its heart
- establish an M.E. platform, similar to that of the Dementias UK Platform, to expedite and consolidate biomedical M.E. research.

Hoping to repeat our success in the Big Give Christmas Challenge (see p 12) for the second time in 2018, this year we will dedicate some of the funds raised to investing in our research-related activity. Building on progress made, we want to:

- work with people affected by M.E. to ensure their voices, views and experience play a lead role in driving research forward.
- actively explore emerging funding opportunities.



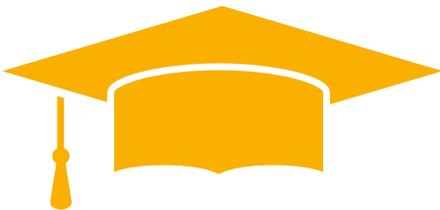
*“We have laid some important foundations, but this is not enough. We need action from the highest level and the CMRC is committed to working with others to drive this. Most importantly, we need to see results now, not in another five years.”*

**Prof Stephen Holgate, Chair, CMRC**

Our funding calls this year resulted in

## £182,000 funding for two PhDs in biomedical M.E. research over three years,

awarded after year-end. These projects will aim to use state-of-the-art technology to look how infection response and brain structure might differ in people with M.E. (compared to health controls), aiming to **inform targeted research into the biological mechanisms of M.E. and highlight possible treatment targets.**



Our PhD studentship at the **University of Edinburgh**, funded jointly with the Scottish Government Chief Scientist Office, was awarded to Prof Chris Ponting in May 2018, while our second award went to Prof Neil Harrison, match-funded by **Brighton and Sussex Medical School**.

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“Thanks Action for M.E. for fighting our corner – **for fundraising to make research happen, for campaigning to get our voice heard, for supporting us lot living with the illness in many ways and for working to raise awareness/ understanding of M.E.**

I’m grateful for that and for all the people who give their time to work/ volunteer for and support the cause. We deserve better. Together we can fight for that.” **Glen, via Facebook.**

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“I’m delighted that the Scottish Government is partnering with Action for M.E. in this exciting initiative.

**Collaborative working like this is so important to enhance vital research into of the causes of M.E.**



– and this in turn has the potential to lead to the development of effective new diagnostic approaches and treatments.”  
**Health Secretary Shona Robison**

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Our films of the 2017 CMRC conference presentations have been

**watched 10,000 times** on YouTube.

# Celebrating your support

Thanks to your incredible support, our **Big Give Christmas Challenge raised an amazing £121,116 online** (including Gift Aid) to help us reach even more people living with M.E. Out of nearly 530 national and local charities chosen to take part, Action for M.E. raised the second highest amount in donations, winning the UK Charity Award in the Big Give Christmas Challenge Awards.

Our 2017 London Marathon runners Stephen Oates, Clare Wills, Amelia Crawford, Chris Hill, Peter Vaiders, Leigh Hovey, Louise Fuller, James Perks, Hannah Gee, Anna White, Janey Drury, Jaynie Rance and Glen Deacon raised an incredible £22,016.

Stephen says: *"Thank you so much for the opportunity to run the London Marathon and raise awareness and funds for Action for ME. It was one of the best experiences in my life and I was proud to wear your vest!"*



Our **Walk with M.E.** fundraiser exceeded all our expectations, with 16 teams raising £4,220. Bethany says: *"As soon as I heard about Walk with M.E., I wanted to get involved. I have had M.E since October 2015. It has had a huge impact on my life, and I went from being very active to being bedbound. There is no way I could walk one million steps on my own, but luckily I will have my lovely team to help me out."*

We are deeply grateful to all of you who **support Action for M.E. throughout the year**, be it a one-off donation, a monthly direct debit, your £21 annual Supporting Membership, or as major donors, making gifts in the thousands. This year saw the relaunch of our Dragonfly Dinner, to celebrate our 30th anniversary, at the V&A Museum, hosted by our President Clare Francis, and working with supporters to extend our reach and raise more money. We look forward to the next Dragonfly Dinner in March 2019.

**Charitable trusts continue to play a central role in our funding, with £193,524 coming from key supporters** including the Robert McAlpine Foundation, the John Swire 1989 Charitable Trust, The De Laszlo Foundation and a generous family trust who match-fund many of our community fundraisers donations. Thanks to these trusts and others, we have been able to deliver essential services to children and adults across the UK, and fund new research into the illness. We are grateful, too, to those whose regional focus ensures we can continue to support people with M.E. across the UK, including the Sir James Reckitt Charity (Hull and East Yorkshire) and the James Tudor Foundation (Bristol, Bath and North East Somerset and Gloucestershire).

Over the years, **gifts left to us in wills** have helped fund research and allowed us to provide information and support to thousands of people with M.E. Last year, we were touched that so many of our supporters chose to remember Action for M.E. in their will, and received £241,545 from legacy gifts.

Thanks to a legacy we received in August, we have been able to develop a plan to advocate for people with M.E. in the UK at World Health Organisation level (see p 8), leading to lasting change – using a legacy left to us, to create a legacy for others.

A further legacy left to us in January also means that we can launch a new pilot service, providing direct one-to-one advocacy to people affected by M.E., a project we have been hoping to fund for a number of years.

Our advocacy service will ensure that those too ill to advocate for themselves are able to secure the services, care and financial support they are entitled to. We will raise understanding with professionals and mainstream advocacy providers to build their capacity and ensure they can meet the needs of people with M.E. in the future.

**We have come so far and we could not have done it without your support. By making donations, running fundraising events from bake sales to sponsored silences, and by talking to others about our work, you are helping us create real change that is so desperately needed for children and adults with M.E. Thank you for your support. Together we can stop M.E. stealing lives.**

# Building on the progress you've helped us make

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“As a health professional, what I feel is missing is peer support for young people and their families. It can be an incredibly isolating condition, impacting school attendance, socialisation and confidence. **I would like to see Action for M.E. providing more of a network for young people...** often the most helpful support is simply the acknowledgement of knowing you are not alone.” Children and Young People’s consultation respondent

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## Over the next three years, we want to improve lives by:

- fundraising to pilot a one-year programme of self-management webinars for 200 people affected by M.E.
- increasing practical support for people with M.E. by linking them with local volunteers
- offering more children and young people with M.E. the opportunity to connect with others affected by the illness, using methods including online platforms and face-to-face meetings to facilitate friendship, support each other and share experiences
- promoting the use of technology to reduce isolation and enable children and young people to access appropriate education through a mobile robot avatar
- developing targeted resources, informed by children, young people and adults with M.E., to ensure that they and their families have the information and support they need.

## Over the next three years, we want to inspire action by:

- fundraising for a Children’s Education Worker to ensure we have the specialist skills and experience needed to best support children, families and professionals
- working collaboratively with education, health and social care professionals to ensure they have access to training, resources and high-quality information about M.E. and its impact
- recruiting a health education specialist for a year to assist us in developing a programme of training and development for primary healthcare professionals so that they have a better understanding of how to meet the needs of people affected by M.E.
- working with M.E. support groups to enhance influence and increase understanding at a local level.

## Over the next three years, we want to invest in change by:

- working with people affected by M.E. to ensure their voices, views and experience play a lead role in driving research forward
- investing in the futures of children and young people with M.E. by increasing volunteer opportunities to develop new and existing skills
- undertaking significant consultation in 2018 – 2019 on the impact of M.E. on health welfare, education, employment and training, to use in our influencing work.

## You can make a difference

You can take action to help end the ignorance, injustice and neglect experienced by children, young people and adults living with M.E. Make a difference by:

- learning more about M.E. and its impact – visit [www.actionforme.org.uk/what-is-me](http://www.actionforme.org.uk/what-is-me)
- becoming a Supporting Member and joining our movement for change – visit [www.actionforme.org.uk/join-us](http://www.actionforme.org.uk/join-us)
- using your skills and experience to help us reach more people with M.E. – visit [www.actionforme.org.uk/volunteer](http://www.actionforme.org.uk/volunteer)
- fundraising to support our work and raise awareness of M.E. – visit [www.actionforme.org.uk/fundraise](http://www.actionforme.org.uk/fundraise)

# How we raised and spent our money 2017 – 2018

Around three-quarters (77%) of our expenditure goes directly towards our charitable activities (see pie chart below). By far the biggest resource needed to deliver these is our experienced and knowledgeable staff team, many of whom have daily one-to-one contact with people affected by M.E. That is why we spend **57% of our total gross expenditure on staff salaries** (including employer National Insurance and pension contribution).

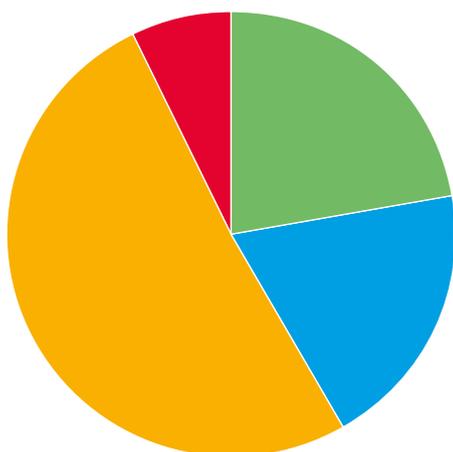
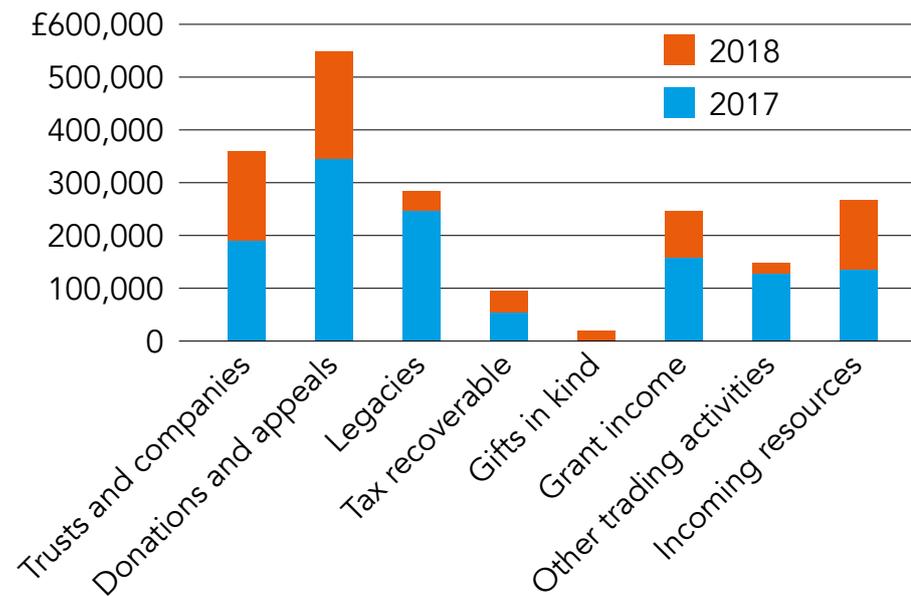
## Incoming resources

We have achieved a sound underlying financial performance for the third year running. Our recorded total income was £1,268,718, up 86% on last year if non-recurring items are included (up 42% if they are discounted).



We aim to raise £3 to £5 for every pound we spend on fundraising, growing our income streams to deliver more services and support.

**During 2017 – 2018, we raised £5.50 for every £1 invested in fundraising.**



## Total resources expended

Overall expenditure was £1,046,797, up 41% on the previous year, reflecting the inclusion of our Children and Young People's Service, the start of our international advocacy programme, and a greater investment in income generation.

Fundraising: Costs of generating voluntary income (£230,864) plus goods and trading (£4,572) = £235,436

Charitable activities: Communications and policy = £202,307

Charitable activities: Information and support services = £533,717

Charitable activities: Research = £75,337

# Statement of financial activities

The positive results for the year have been underpinned by continuing success within our core income streams, a significant increase to donations thanks to the Big Give Christmas Challenge, and two legacies totalling £203,496. In addition, the QMUL Brain in Pain study (see p 29) has concluded at a significantly lower overall cost than originally thought, and has resulted in a comparatively large rebate which has been reported as grant income. This is allowing us to invest in two biomedical PhD studentships and a research fellowship.

## Our income and expenditure

Taking the above into consideration, Action for M.E. has achieved a sound underlying financial performance for the third year running. Our recorded total income was £1,268,718 which is up 86% on last year if non-recurring items are included, and up 42% if they are discounted. The non-recurring items included crystallising the large legacy reported as a contingent asset within the 2016 – 2017 financial year.

This year also saw the inclusion of Children and Young People's Services following the merger with the Association of Young People with M.E. This was enacted on 2 April 2017 and is fully reflected within the accounts.

Overall expenditure was £1,046,797, which is up 41%, reflecting the inclusion of Children and Young People's Services, the start of our international advocacy programme, and a greater investment in income generation. The net result is an overall surplus of £221,921. At the year end, unrestricted reserves were £499,253 (up £100,884) of which £193,752 were designated funds in support of our international advocacy and regional advocacy

projects. Restricted reserves were £233,449 (up £121,037) of which £90,667 will be expended over the course of the next year on our two PhDs and research fellowship.

We continue to monitor the level of reserves to ensure we can maximise the work we do while ensuring the charity has a strong medium-term financial position.

Despite being the largest UK charity for people with M.E. in the UK, we have a (full-time equivalent) staff team of just 17 and, in comparison to the scale of the challenge, very limited capacity and resources, dwarfed by the urgent and often complex needs of 250,000 men, women and children living with M.E., plus the family members, friends, employers and professionals trying to support them. With vital support from our donors and supporters, we strive to strengthen our financial position and bring in the income needed to deliver the promises we make to children and adults affected by M.E.

We aim to raise £3 to £5 for every pound we spend on fundraising, growing our income streams to increase the amount we can spend delivering our services and support. During 2017 – 2018, we raised £5.50 for every £1 invested in fundraising.

## Balance sheet

The surplus generated from activities has increased our accumulated funds and cash reserves at the year end. Unrestricted reserves have increased primarily due to legacy income and donations in the year and restricted reserves have increased due to a rebate on the Brain in Pain study.

## Funding sources

The principal funding sources for Action for M.E. are charitable trusts, community fundraising and events, Supporting Membership income, and individual gifts. Other funding sources include Big Lottery Fund, Scottish Government grants, Gift Aid, legacies and Christmas card sales. We continue to ensure a broad enough funding base to mitigate potential risk.

## 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 longterm investment. The charity has an investment policy which currently uses the COIF Charities Investment Fund to provide a short term interest-bearing account that optimises the balance between flexibility and rate of return.

## Reserves policy

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

Available unrestricted funds at 31 March 2018 increased to £499,253, equating to 6.6 months at an average monthly spend rate of £76,000 within unrestricted funds. The Trustees agreed the allocation of £125,000 from general funds to designated funds to achieve the ambitious objectives set out in our revised 2016 – 2021 strategy. This was comprised of two amounts; firstly, an additional amount of £45,000 for our international advocacy work, making a total designated in the last two years of £125,000 (of which £113,752 was

remaining at the year end); and secondly, an amount of £80,000 for our pilot regional advocacy service (all of which was remaining at the year end). Further details are set out in note 12 to the accounts on p 32. This results in the remaining general funds standing at £305,501 which equates to 4.5 months of unrestricted running costs.

### 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.

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 Stephens was appointed as our new auditor at the 2017 Annual General Meeting.

### Provision of information to Auditor

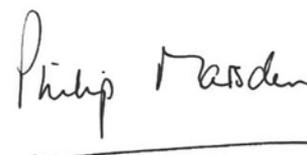
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish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



Jonah Grunsell  
Chair of Board of Trustees and Directors



Philip Marsden  
Director and Treasurer

Approved by the Board of Trustees and signed on its behalf on 30 October 2018

# 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 Society provides on pages 3 to 15.

## Trustees

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

The Board of Trustees of Action for M.E. meets quarterly with the Chief Executive and relevant staff to exercise corporate governance, 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 Chief Executive, whose quarterly reports to the Board include a report against key performance indicators identified in our high level delivery plan.

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

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

Supporting Members are asked to vote on new appointments and the reelection of existing Trustees. These results were subsequently confirmed at our annual general meeting in November 2017. Each new Trustee receives a full induction and the opportunity to be paired with a 'buddy' for the first year on the Board, and access to ongoing training.

## 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 and Communications Group meets quarterly and provides a steer for the charity's policy, influencing and communications work.
- 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.
- We will establish a Communications and Marketing Group in 2018 – 2019, with the aim of raising awareness and understanding of M.E., and promoting the services and support offered by Action for M.E.

## 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.

## Volunteers

Much of the work we do is made possible by our fantastic volunteers. Some, like Diane (see below), have been with us for many years, while others gain valuable work experience over shorter periods. Some of our volunteers work with us in our Bristol office, while others make their essential contribution from home.

Some key services for our children and young people's community are led by young volunteers living with M.E. Some contribute to our community forum, helping users feel less isolated and more confident about making connections. Others write to those children and young people severely affected by M.E., without the expectation of a reply. One told us that volunteering with us "gave me the confidence to look into the real world."

A range of medical, research and professional advisors also provide an invaluable network of support on a pro bono basis.

All have one thing in common: they are hugely valued not just by our staff and Trustees, but also the people with M.E. they help us support. We are immeasurably grateful for the time and energy they spend enriching our work, and helping us reach even more people affected by M.E.

## Collaborative partners

We are committed to working collaboratively with others to improve the lives of people with M.E. This includes other M.E. charities and patient organisations, health, social care and education professionals, government and senior officials, and other decision-makers.

As a member of a number of organisations and alliances, including Forward M.E., Disability Rights UK and the Disability Benefits Consortium, we continue to build capacity, reach more people, and achieve more by working in partnership to achieve common goals. We also provide secretariat

support to the UK CFS/M.E. Research Collaborative (see p 10), and lead an international alliance of patient organisations committed to influencing international decisions that affect national policies on M.E. in the UK. At the time of writing, this alliance included:

- ACAF Associació Catalana d'Afectades i Afectats de Fibromiàlgia i d'altres Síndromes de Sensibilització Central, Spain
- The American ME and CFS Society, United States
- Associated New Zealand ME Society, New Zealand
- Emerge Australia, Australia
- Forward ME, United Kingdom
- Japan ME Association, Japan
- ME CFS Foundation South Africa, South Africa
- Plataforma Familiars Fm-SFC-SQM, Spain
- Welsh Association of ME & CFS Support, United Kingdom.



## Believing in our volunteers

Diane Shortland began volunteering for Action for M.E. 10 years ago, when she was housebound and dependent on others for much of her daily care. Joining us as co-ordinator for the audio-recording of our membership magazine, *InterAction*, she became one of our regular writers as her health improved.

*"Having a long-term illness can be so isolating and it's hard not to feel of little value to society. Action for M.E. does the opposite and pioneers the worth of disabled people and believes in their capabilities. I could have done nothing occupationally for the last decade but I'm so glad I didn't. I have achievements now to be proud of and largely that is thanks to this organisation having some faith in me. For that, I will always be grateful. Keep up the good work Action for M.E., and I will always remain keen to be part of your journey, our journey, to provide a better quality of life for people with M.E. and greater understanding of this hugely misunderstood illness."*

## 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 38. 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 (IoF) Code of Fundraising Practice, the Data Protection Act 1998 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.

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

## Risk

The Risk Register is reviewed regularly by the Audit, Finance and Fundraising Committee and annually by the Board. Until the Chief Operating Officer was appointed in September 2017, the Director of Services and Development was responsible for the Risk Register and reported directly to the Chief Executive. 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. Since the launch of our Children and Young People's Service, the necessary safeguarding training has been built into our organisational induction process (we also have a safeguarding Trustee lead) to ensure that children and vulnerable adults are always safeguarded by Action for M.E.

During 2017 – 2018, Trustees were satisfied that this was undertaken in a proper manner and took a proactive role in supporting additional work in this area.

## You can stop M.E. stealing lives

You can take action to help end the ignorance, injustice and neglect experienced by children, young people and adults living with M.E. Make a difference by:

- learning more about M.E. and its impact – visit [www.actionforme.org.uk/what-is-me](http://www.actionforme.org.uk/what-is-me)
- becoming a Supporting Member and joining our movement for change – visit [www.actionforme.org.uk/join-us](http://www.actionforme.org.uk/join-us)
- using your skills and experience to help us reach more people with M.E. – visit [www.actionforme.org.uk/volunteer](http://www.actionforme.org.uk/volunteer)
- fundraising to support our work and raise awareness of M.E. – visit [www.actionforme.org.uk/fundraise](http://www.actionforme.org.uk/fundraise)

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

## Opinion

We have audited the financial statements of Action for M.E. (the 'charitable company') for the year ended 31 March 2018 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 2018 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- have been prepared in accordance with the requirements of the Companies Act 2006, the Charities Act 2011, the Charities and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended).

## Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

## Conclusions relating to going concern

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

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

months from the date when the financial statements are authorised for issue.

## Other information

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

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

We have nothing to report in this regard.

## Opinions on other matters prescribed by the Companies Act 2006

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

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

## Matters on which we are required to report by exception

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

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

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

## Responsibilities of Trustees

As explained more fully in the Trustees' responsibilities Statement set out on p 21, the Trustees are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the Trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

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

## Auditor's responsibilities for the audit of the financial statements

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

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](http://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  
Stephens, Statutory Auditor,  
Bath UK

Wednesday 31 October 2018

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

## Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2018

	Notes	Unrestricted funds (£)	Restricted funds (£)	Total 2018 (£)	Total 2017 (£)
<b>Incoming resources</b>					
Incoming resources from generated funds:					
Donations and legacies	3	725,661	283,120	1,008,781	528,557
Other trading activities	3	112,268	16,198	128,466	19,569
Investment income	4	293	3	296	675
Incoming resources from charitable activities	3	93,858	37,317	131,175	132,886
<b>Total incoming resources</b>		<b>932,080</b>	<b>336,638</b>	<b>1,268,718</b>	<b>681,687</b>
<b>Resources expended</b>					
Costs of generating funds:					
Costs of generating voluntary income	5	230,864	–	230,864	181,888
Fundraising trading: costs of goods sold and other costs		4,572	–	4,572	3,420
Charitable activities	5	595,760	215,601	811,361	555,826
<b>Total resources expended</b>		<b>831,196</b>	<b>215,601</b>	<b>1,046,797</b>	<b>741,134</b>
Net movement in funds	12	100,884	121,037	221,921	(59,447)
Reconciliation of funds					
Fund balances at 1 April 2017		398,369	112,412	510,781	570,228
<b>Fund balances at 31 March 2018</b>		<b>499,253</b>	<b>233,449</b>	<b>732,702</b>	<b>510,781</b>

All incoming resources and resources expended derive from continuing operations. The notes on p 25 to 34 form an integral part of these accounts.

# Balance sheet

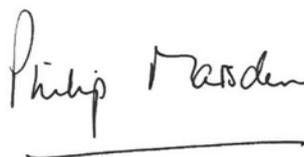
As at 31 March 2018 (company registered number 2906840)

	Notes		2018 (£)	2017 (£)
<b>Fixed assets</b>				
Tangible assets	9		2,146	4,396
<b>Current assets</b>				
Debtors	10	111,925	32,360	
Cash at bank and in hand		691,592	519,935	
Total current assets		803,517	552,295	
Creditors: amounts falling due within one year	11	(72,961)	(45,910)	
Net current assets			730,556	506,385
Total assets less current liabilities			732,702	510,781
<b>Capital and reserves</b>				
Unrestricted funds:				
General funds	12		305,501	313,369
Designated funds	12		193,752	85,000
			499,253	398,369
Restricted funds	13		233,449	112,412
Accumulated funds			732,702	510,781

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 25 to 34 form an integral part of these accounts



Jonah Gunsell  
Chair of Board of Trustees and Directors



Philip Marsden  
Treasurer

Approved by the Board of Trustees on 30 October 2018

Action for M.E. cash flow statement for the year ended 31 March 2018

		<b>2018</b>	<b>2017</b>
Net cash flow from operating activities	See note a below	172,214	(71,820)
Net cash flow from investing activities	See note b below	(557)	(2,655)
Net increase in cash and cash equivalents		<u>171,657</u>	<u>(74,475)</u>
Cash and cash equivalents at beginning of period		519,935	594,410
Cash and cash equivalents at end of period		<u>691,592</u>	<u>519,935</u>

Notes to the cash flow statement

<b>a</b>	<b>Cash flows from operating activities</b>		
		£	£
	Net movement in funds	221,921	(59,447)
	Depreciation	3,103	4,872
	Financial income	(296)	(675)
		<u>224,728</u>	<u>(55,250)</u>
	(Increase)/decrease in debtors	(79,565)	27,605
	(Decrease)/increase in creditors	27,051	(44,175)
	NET CASH FROM OPERATING ACTIVITIES	<u>172,214</u>	<u>(71,820)</u>
<b>b</b>	<b>Cash flows from investing activities</b>		
		£	£
	Purchase of tangible fixed assets	(853)	(3,330)
	Interest received	296	675
	NET CASH FROM INVESTING ACTIVITIES	<u>(557)</u>	<u>(2,655)</u>

# 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 2015) 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 38. 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 Commissioners for England & Wales, grants received in advance and specified by the donor as being subject to specific terms and conditions are deferred until the conditions applying to the grant are within the control of the charity and it is probable that the imposed terms and conditions can be met. Such deferrals are shown in the notes to the accounts and the sums involved are shown as creditors in the accounts.

### Recognition of liabilities

Liabilities are recognised on the accruals basis.

### Incoming resources

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

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

### Resources expended

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

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

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

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

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

Support costs include all expenditure not directly related to charitable activity. The Trustees have applied what they consider to be reasonable judgements in apportioning such costs between direct charitable costs and support costs. The central office functions such as general management, payroll administration, budgeting and accounting, information technology, human resources and financing, are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of the cost allocation is explained in note 5 to the accounts.

Governance costs are the costs associated with the governance arrangements of the Charity which relate to the general running of the Charity as opposed to those costs associated with fundraising or charitable activity. Included within this category are the cost of audit fees and costs linked to the strategic management of the Charity. Governance costs are allocated across the categories of charitable expenditure and the costs of generating funds. The basis of allocation is explained in note 5 to the accounts.

### Fixed assets and depreciation

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

### Pensions

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

### Taxation

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

### Operating lease agreements

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

### Financial instruments

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

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

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

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

## 3 Details of incoming resources

	Unrestricted funds (£)	Restricted funds (£)	Total 2018 (£)	Total 2017 (£)
<b>Donations and legacies</b>				
Trusts and companies	126,124	67,400	<b>193,524</b>	164,993
Donations and appeals	308,576	51,954	<b>360,530</b>	186,543
Legacies	241,545	–	<b>241,545</b>	39,805
Tax recoverable	45,416	6,970	<b>52,386</b>	41,432
Gifts in kind	4,000	–	<b>4,000</b>	10,000
Grant Income	–	156,796	<b>156,796</b>	85,784
	<b>725,661</b>	<b>283,120</b>	<b>1,008,781</b>	528,557
<b>Other trading activities</b>				
Lotteries and raffles	11,553	–	<b>11,553</b>	11,874
Christmas cards	4,229	–	<b>4,229</b>	4,732
Supplement commission	1,961	–	<b>1,961</b>	2,670
Merchandise	377	328	<b>705</b>	61
Events	94,050	–	<b>94,050</b>	–
Other	98	15,870	<b>15,968</b>	232
	<b>112,268</b>	<b>16,198</b>	<b>128,466</b>	19,569
<b>Incoming resources from charitable activities</b>				
Subscriptions	91,647	1,262	<b>92,909</b>	97,029
Conference fees	–	36,055	<b>36,055</b>	31,299
Charity journal	2,041	–	<b>2,041</b>	3,024
Information and publications	170	–	<b>170</b>	1,534
	<b>93,858</b>	<b>37,317</b>	<b>131,175</b>	132,886

Grant income included a rebate of £73,867 from QMUL as a rebate from the Brain in Pain study which concluded at significantly lower cost than originally expected – see p 29.

Details of 2017 income	Unrestricted funds (£)	Restricted funds (£)	Total 2017 (£)
<b>Donations and legacies</b>			
Trusts and companies	107,832	57,161	164,993
Donations and appeals	152,176	34,367	186,543
Legacies	39,805	–	39,805
Tax recoverable	38,088	3,344	41,432
Gifts in kind	10,000	–	10,000
Grant Income	–	85,784	85,784
	<b>347,901</b>	<b>180,656</b>	<b>528,557</b>
<b>Other trading activities</b>			
Lotteries and raffles	11,874	–	11,874
Christmas cards	4,732	–	4,732
Supplement commission	2,670	–	2,670
Merchandise	61	–	61
Other	232	–	232
	<b>19,569</b>	<b>–</b>	<b>19,569</b>
<b>Incoming resources from charitable activities</b>			
Subscriptions	96,659	370	97,029
Conference fees	–	31,299	31,299
Charity journal	3,024	–	3,024
Information and publications	1,534	–	1,534
	<b>101,217</b>	<b>31,669</b>	<b>132,886</b>

#### 4 Investment income

	2018 (£)	2017 (£)
Interest from cash investments in the UK	296	673
Interest from Gift Aid and covenants	–	2
	<b>296</b>	<b>675</b>

## 5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2018 (£)	Total 2017 (£)
<b>Costs of generating voluntary income</b>				
Staff costs	42,939	–	<b>42,939</b>	96,304
Direct fundraising costs	77,453	–	<b>77,453</b>	36,977
Support costs – see below	110,472	–	<b>110,472</b>	48,607
	<b>230,864</b>	–	<b>230,864</b>	<b>181,888</b>
	Unrestricted funds (£)	Restricted funds (£)	Total 2018 (£)	Total 2017 (£)
<b>Charitable activities</b>				
Communications and policy	202,307	–	<b>202,307</b>	92,542
Information and services	378,110	155,607	<b>533,717</b>	322,644
Research	15,343	59,994	<b>75,337</b>	140,640
	<b>595,760</b>	<b>215,601</b>	<b>811,361</b>	<b>555,826</b>

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

Activity	Activities undertaken directly	Support costs as below	Total (£)
Communications and policy	85,697	116,610	<b>202,307</b>
Information and services	215,471	162,639	<b>378,110</b>
Research	–	15,343	<b>15,343</b>
	<b>301,168</b>	<b>294,592</b>	<b>595,760</b>

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 £
<b>Support costs</b>						
Communications and policy	14,251	17,011	11,929	64,310	9,109	<b>116,610</b>
Information and services	19,876	23,726	16,637	89,695	12,705	<b>162,639</b>
Research	1,875	2,238	1,569	8,462	1,199	<b>15,343</b>
	36,002	42,975	30,135	162,467	23,013	<b>294,592</b>
Fundraising	13,501	16,116	11,301	60,925	8,630	<b>110,473</b>
	<b>49,503</b>	<b>59,091</b>	<b>41,436</b>	<b>223,392</b>	<b>31,643</b>	<b>405,065</b>

Office costs include £4,000 (2017: £10,000) for professional services in kind.

	2018 (£)	2017 (£)
<b>Governance costs</b>		
Administrative salaries – based on time spent	<b>18,054</b>	14,663
Indemnity insurance for Trustees	<b>1,499</b>	1,407
Governance training	<b>529</b>	193
Trustees' expenses	<b>2,218</b>	2,426
Meeting room hire and refreshment costs	<b>441</b>	15,949
Auditors' fees	<b>6,513</b>	7,825
Professional fees	<b>19,699</b>	11,485
Design and printing	<b>550</b>	–
	<b>49,503</b>	53,948

	2018 (£)	2017 (£)
<b>Grant activities</b>		
Buckinghamshire New University – Disease Register	–	6,882
Queen Mary University London – Brain in Pain	–	37,094
University of Newcastle – Autonomic Dysfunction	–	7,500
	–	51,476

## 6 Net movement in funds

	2018 (£)	2017 (£)
<b>This is stated after charging:</b>		
Operating lease	<b>35,825</b>	24,219
Depreciation of owned fixed assets	<b>3,103</b>	4,872
Auditor remuneration	<b>6,513</b>	7,825
Trustees' expenses	<b>2,443</b>	2,426
Pension costs	<b>13,379</b>	8,419

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 2018 was £1,499 (in 2017 it was £1,407).

## 7 Staff costs and emoluments

	2018 (£)	2017 (£)
Gross salaries	<b>537,205</b>	383,124
Employer's National Insurance	<b>49,210</b>	27,391
Pension contributions	<b>13,379</b>	8,419
	<b>599,794</b>	418,934

### Numbers of full-time employees or full-time equivalents

	2017-18	2016-17
Engaged on charitable activities	<b>9</b>	9
Engaged in fundraising activities	<b>4</b>	2
Engaged on management and administration	<b>4</b>	2
	<b>17</b>	<b>13</b>
The number of employees whose emoluments as defined for taxation purposes amounted to over £60,000 in the year was as follows:	<b>Number</b>	Number
	<b>1</b>	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 £101,338 (2017: £94,282).

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

	2018 (£)	2017 (£)
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.	<b>2,443</b>	2,426
Amounts of expenses incurred by Trustees that were donated back to the charity.	<b>1,011</b>	1,435
There were no related party transactions up to 31 March 2018.		

## 9 Tangible fixed assets

	Office equipment 2018 (£)
<b>Cost</b>	
At 1 April 2017	50,014
Additions for year	853
Disposals in year	–
<b>At 31 March 2018</b>	<b>50,867</b>
<b>Depreciation</b>	
At 1 April 2017	45,618
Charge for year	3,103
Disposals in year	–
<b>At 31 March 2018</b>	<b>48,721</b>
<b>Net book value</b>	
At 31 March 2017	4,396
<b>At 31 March 2018</b>	<b>2,146</b>

## 10 Debtors

	2018 (£)	2017 (£)
Trade debtors	<b>352</b>	311
Prepaid expenses	<b>23,379</b>	26,810
Due from HMRC	<b>950</b>	436
Accrued income	<b>87,244</b>	4,803
	<b>111,925</b>	32,360

## 11 Creditors: amounts falling due within one year

	2018 (£)	2017 (£)
Trade creditors	17,733	18,077
Deferred income (see note a below)	–	14,500
Accrued Expenses	38,448	10,625
Unpaid pension contributions	2,032	2,708
Other taxation and social security costs	14,748	–
	<b>72,961</b>	45,910
Note a: Movement of deferred income		
Deferred income b/f	14,500	
Amount released in the year	(14,500)	
Amount deferred in the year	–	
<b>Deferred income at 31 March 2018</b>	<b>–</b>	

Deferred income consists of conference income, with the event taking place in September 2018.

## 12 Funds

	General funds (£)	Designated funds (£)	Total (£)
<b>Statement of unrestricted funds</b>			
Balance at 1 April 2017	313,369	85,000	<b>398,369</b>
Transfer between funds	(125,000)	125,000	–
Surplus for year	117,132	(16,248)	<b>100,884</b>
<b>Balance at 31 March 2018</b>	<b>305,501</b>	<b>193,752</b>	<b>499,253</b>

Designated funds represents £113,752 for the remaining balance of two years of international advocacy work, and £80,000 for our pilot advocacy service.

	Tangible fixed assets (£)	Cash	Other Net current assets (£)	Total (£)
<b>Analysis of net assets between funds – current year</b>				
Unrestricted funds:				
General funds	2,146	364,391	38,964	<b>305,501</b>
Designated funds	–	193,752	–	<b>193,752</b>
	2,146	458,143	38,964	<b>499,253</b>
Restricted funds	–	233,449	–	<b>233,449</b>
	2,146	691,592	38,964	<b>732,702</b>

	Tangible fixed assets (£)	Cash	Other Net current liabilities (£)	Total (£)
<b>Analysis of net assets between funds – prior year</b>				
Unrestricted funds:				
General funds	4,396	322,523	(13,550)	<b>313,369</b>
Designated funds	–	85,000	–	<b>85,000</b>
	4,396	407,523	(13,550)	<b>398,369</b>
Restricted funds	–	112,412	–	<b>112,412</b>
	<b>4,396</b>	<b>519,935</b>	<b>(13,550)</b>	<b>510,781</b>

## 13 Restricted funds

	Opening balances £	Incoming resources £	Outgoing resources £	Closing Balances £
<b>Movements in restricted funds</b>				
Research	75,206	158,346	59,994	<b>173,558</b>
Scotland services	–	9,000	9,000	–
Peer mentoring	16,556	63,703	46,111	<b>34,148</b>
Improving support for care pathways	20,000	–	20,000	–
Hear M.E., influence M.E.	650	–	650	–
Children’s Services	–	69,363	69,363	–
Connect M.E.	–	15,000	–	<b>15,000</b>
Educate M.E.	–	9,966	1,223	<b>8,743</b>
Support M.E.	–	9,260	9,260	–
Regional advocacy	–	2,000	–	<b>2,000</b>
	<b>112,412</b>	<b>336,638</b>	<b>215,601</b>	<b>233,449</b>

**Research** – donations are regularly received from donors wishing to see advances in research. Three pilot research studies have been supported in part from this fund during the year. See the grant activities table on p 29 for more details.

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

**Peer mentoring** – funded by Health and Social Care Alliance Scotland from the Transforming Self-Management in Scotland Fund, the Mentor M.E. pilot project will develop a network of volunteer peer mentors supporting people living with M.E. in Scotland. We began recruiting volunteers for this in December 2016, and are matching mentors with those who feel they would benefit from one-to-one mentoring support.

**Improving support for care pathways** – received from the Scottish Government for a project aimed at improving care pathways in Scottish health services.

**Hear M.E., influence M.E.** – funded by a Big Lottery Awards for All Scotland grant, this project brought people affected by M.E. together to identify challenges and possible solutions to a number of aspects of living with M.E.

**Children’s and Young People’s Services** – Children and Young People’s Service – donations for our work with children and young people (aged up to and including 18 years) living with M.E., and their family, ensure the continuation of our complex case work and peer-support services, such as our young people’s forum.

**Connect M.E.** – This project is part-funded thanks to an individual donation, and aims to use technology to connect people with M.E. with healthy volunteers who want to offer specific support.

**Educate M.E.** – This project will work with families to co-produce and deliver awareness-raising among education professionals in order to build the capacity of schools to provide support to children and young people with M.E. and their families.

**Support M.E.** – This Awards for All grant funded one consultation event for stakeholders at our 2017 AGM and conference, offering them the opportunity to input into our new Children and Young People’s strategy.

**Regional advocacy** – Throughout the Southwest and Midlands, this project aims to develop a telephone and face to face advocacy service, enabled by 30 volunteers and two paid advocates, and overseen by an Advocacy Coordinator as part of a two-year pilot.

## 14 Pension commitments

The charity operates a defined contribution pension scheme. The pension cost charge for the year represents contributions payable to the scheme and is disclosed in note 7. Contributions in the sum of £2,032 (£2,708 in 2017) were outstanding at the balance sheet date.

## 15 Operating leases

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

	Total Leases 2018(£)	Total Leases 2017(£)
<b>Operating lease payments falling due:</b>		
within one year	26,462	25,276
within two to five years	52,200	73,656
over five years	–	–
	<b>78,662</b>	<b>98,932</b>

## 16 Contingent assets

During the year the charity has been advised of a number of legacies and received significant amounts during the year. There are no contingent assets to report for FY 17/18.

## 17 Research funding commitments

The charity is committed to funding a number of research grants over forthcoming years subject to certain performance conditions being met. The charity is committed to further expenditure of £212,000 of which £90,667 is to be spent in the year to 31 March 2019.

## Legal and administrative details

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

Registered office  
42 Temple Street, Keynsham,  
Bristol BS31 1EH

President  
Clare Francis MBE

Founding President  
Sue Finlay

Vice President  
Martin Arber

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

## Trustees and Directors 2017 – 2018

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Philip Marsden, Treasurer  
Gordon Berry  
Christopher Cundy  
Sue Hardy  
Jane Stacey  
Katherine Thomas  
Jane Young  
Colin Batten (from 3 Apr 17)  
Andy Dougan (from 16 Nov 17)  
Ed Stephens (from 16 Nov 17)  
Ondine Upton (until 2 Apr 17)  
Charlie Stockford (until 5 May 17)  
Jane Logan (until 16 Nov 17)  
Dr Gregor Purdie (until 16 Nov 17)

### Chief Executive

Sonya Chowdhury

### Principal Medical Advisers

Dr Gregor Purdie  
Prof Julia Newton

### Bankers

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

### Auditor

Moore Stephens  
30 Gay Street, Bath BA1 2PA

## References

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3. National Institute of Health and Care Excellence (2007) Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management; guideline CG53.
4. 2020health (2017) Counting the cost: M.E./CFS.
5. Radford and Chowdhury (2016) M.E./CFS Research Funding; commissioned by the UK CFS/M.E. Research Collaborative.

“Thanks for all your work at Action for M.E.  
It has been a huge help to me!”

Julie, by email



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