



Improving lives through action

Trustees report
2016 – 2017



What is M.E.?

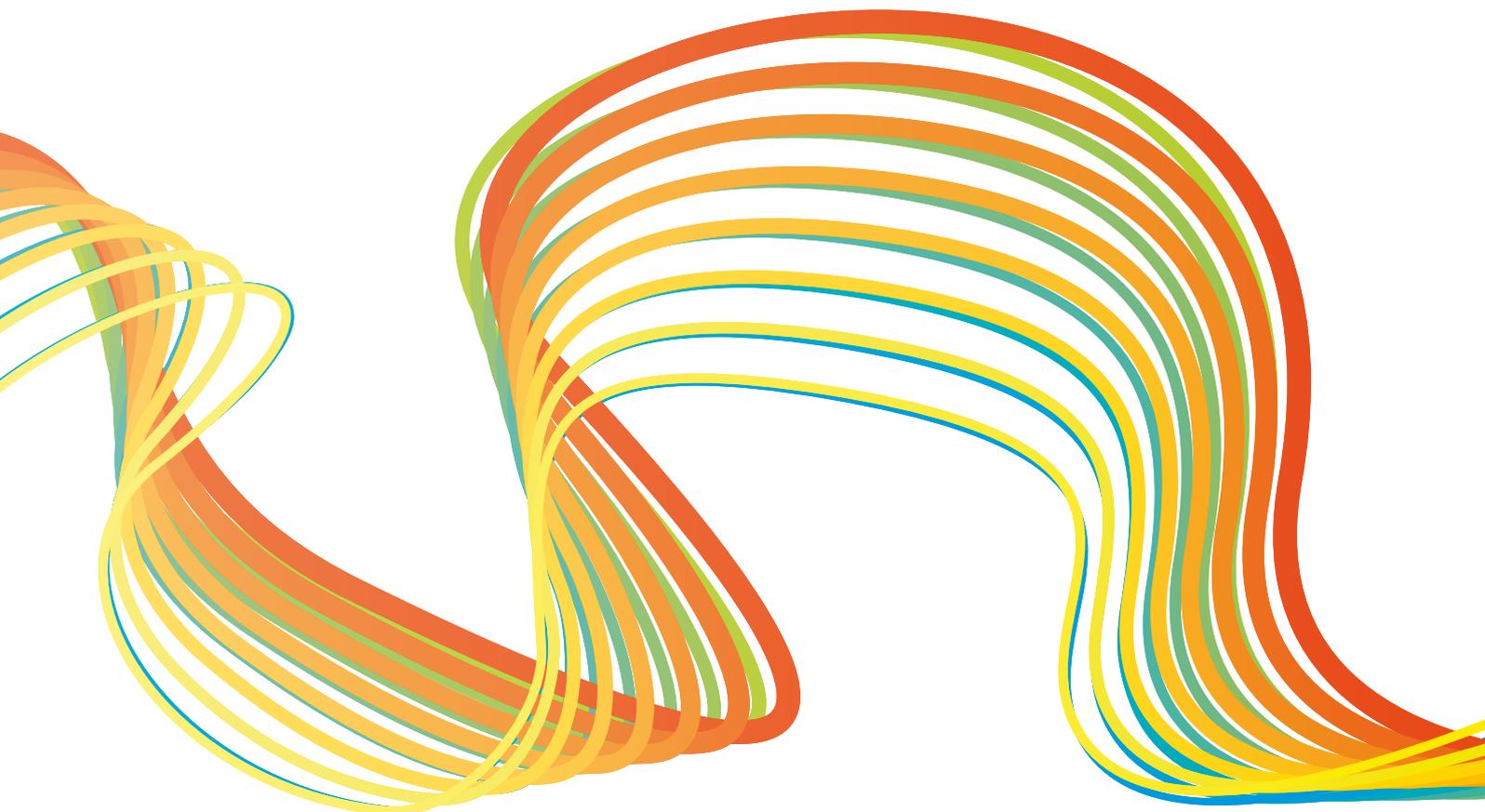
Imagine having months off from work because you are so ill that you are no longer able to tell the time when you look at the face of a clock. Pain and fatigue are your constant companions and, though you sleep most of the time, you never feel rested.

That is the experience of many thousands of people with the chronic neurological condition myalgic encephalomyelitis (M.E.), sometimes diagnosed as chronic fatigue syndrome (CFS, or M.E./CFS). Its key symptom is severe, persistent fatigue associated with post-exertional malaise, the body's inability to recover after expending even small amounts of energy, leading to a flare-up in other symptoms.

There are around 250,000 men, women and children who have M.E. in the UK, and 17 million worldwide. One in four people with M.E. are living with the most severe form of the illness, leaving them house- and or bed-bound for months and even years.

M.E. can affect anyone, at any time. Though it affects more women than men, M.E. does not discriminate: people tell us that they thought it would never happen to them. That's why Action for M.E. takes action to end the ignorance, injustice and neglect they face every day.

You can find out more about M.E., and the difference Action for M.E. is making, at www.actionforme.org.uk



On the cover is Shass Blake, who has M.E. Shass was also pictured on the cover of our 2016 - 2021 strategy, and continues to reach out to others with the condition, leading a local M.E. support group in Bristol.

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Winning hearts and minds

Action for M.E. leads change by putting people with M.E. at the heart of everything it does. Over the next four years, the purpose of our 2016 – 2021 strategy is to end the ignorance, injustice and neglect experienced by people with M.E., helping to provide them with essential care and support.

To truly transform lives, we need to create a critical mass and a stronger voice to advocate for the change people affected by M.E. so desperately need and deserve. Without the support of our wonderful donors, supporters, volunteers and fundraisers, we cannot achieve what we do: thank you to each and every one of you.

I am delighted that our Board of Trustees is able to report a sound financial performance by Action for M.E. for the third year running – you can read more about this on p 18, including how our results for this year have been significantly affected by the timing of legacy receipts.

In April 2017, we launched our new Children's Services after merging with the Association of Young People with M.E. Since then, we have been working in partnership with a group of children, parents and professionals to undertake a consultation to inform the development of our new services.

The level of need is so high, and a lack of understanding about M.E. affects access to education, health and social care: as our research shows, a disproportionate number of families are also subjected to unnecessary child protection proceedings. This is unacceptable, and we will increase our work to tackle this directly.

We know what needs to be done, and we have the drive and ambition to make this happen. We may not be in a position to eradicate the illness and achieve our vision of a world without M.E. – yet. But as this report shows, by working together we are in a position to make a real and lasting difference.



Sonya Chowdhury
Chief Executive

Winning through action

If we are to really make a difference to the thousands of individuals with M.E., we must work together to ensure M.E. is more than just a poorly understood condition on the fringes of medicine, research and public awareness.

I have not directly experienced the pain, the isolation and the multitude of debilitating challenges that people with M.E. and their loved ones face on a daily basis. However, I do not believe that this is a barrier to performing effectively as the role of Chair of the Board of Action for M.E.

We must mobilise the support of people just like me, who are at least for now, relatively unaffected by it directly or indirectly. We must actively influence and inform decision-makers in the UK and globally, engage medical and social care professionals, and educate the general public to build understanding, awareness and commitment.

An exceptional step for us was the launch of the UK M.E./CFS Biobank, on M.E. Awareness Day in May. This unique resource, of which Action for M.E. is incredibly proud to be a founding co-funder, shows what can be achieved when organisations are committed to collaboration: now open to researchers across the world, it has since received two funding awards from the National Institutes of Health.

By working together like this in proactive partnership, and drawing on the incredible set of experience, skills and expertise of the Action for M.E. team along with the wider M.E. community, we can achieve our aims and deliver our strategy. Most importantly, we can make our vision of a world without M.E. a reality.



Jonah Grunsell
Chair of Board of Trustees

Our vision is a world without M.E.

Launched in July 2016, our exciting five-year strategy set out our promises to improve the lives of people with M.E., inspire action at all levels, and invest in change.



Opposite you can see the difference we made 2016 – 2017, and on the pages that follow we describe how we are working to meet the needs of people affected by M.E. by providing support and services now, while taking action to secure change for the future. On page 16 you can

see how we intend to build on the difference we have already made to bring about real and lasting change. This is just the beginning.

We ask those who share our vision and values to join us. You can make a difference by understanding key

facts about M.E. and its impact on those affected, and sharing your skills, expertise and time to support our work. Together, we can take action to end the ignorance, injustice and neglect experienced by those whose lives have been stolen by M.E.

2016 – 2017: the difference we made



£28,860

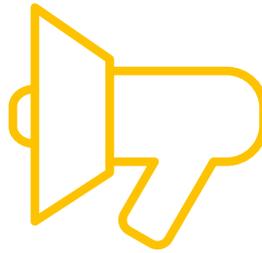
How much our brilliant London Marathon runners raised this year

24



The number of weekly one-to-one telephone/email support sessions (more than 1,220 over the year) for those seeking information, advice and support.

110,730



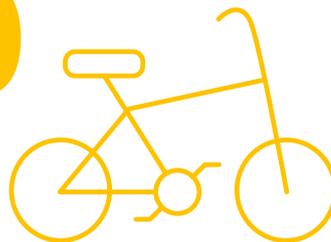
Average weekly circulation of Action for M.E. stories, letters and interviews in local and national press (or 5,758,000 over the year)



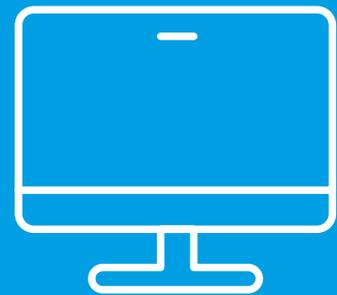
150,000

Facebook users who saw our #dontignoreME films for M.E. Awareness Week. One said: "To all those who suffer from M.E., know that some of us do care and are trying to get others to understand. Don't give up."

£10,660



The fantastic sum raised by our 2016 Ride London team, the highest ever raised for us in this event.



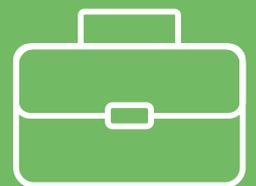
Nearly

30

times every hour

The number of visits to our Online M.E. Centre (240,000 over the year) by people seeking information and support about M.E.

M.E. and work



The most frequently requested new information resource produced by Action for M.E. over the 12 months, our *M.E. and work* booklet aims to support people with M.E. to stay in or return to work, or leave work well.

“There were a number of occasions, especially during the early years, when I was effectively housebound for days on end. Simply rising, showering and dressing could disable me for the rest of the day. My GP was sympathetic and understanding, but offered no real help. There were others in the joint practice who were clearly sceptical about the condition.

“I joined Action for M.E. once I’d been diagnosed and continued my membership for the first year. They most importantly provided me with support in the form of information I wasn’t given by the medical profession. Amongst this was literature on pacing, a technique I employed with varying degrees of success during the ten years I suffered from the condition. I also received information describing the various symptoms and advice on how to deal with many of these. Being part of a community was so helpful.”

Stuart, via email

Improving lives: offering targeted information and support

Knowing as much as you can about the services and support you are entitled to means that you can advocate for yourself more effectively to access the care you need – and deserve.

On average, our booklets, factsheets and other information resources were downloaded and/or posted out around 560 times each month, and our Information and Support Officers gave one-on-one support to more

than 1,220 people by phone or email over the year – that's the equivalent of 24 each week.

We share clear information based on published evidence and the experiences of people with M.E. via our Online M.E. Centre, which was visited by people seeking information and support about M.E. nearly 244,000 times this year – that's the equivalent of almost 30 times every hour. Nearly 40,000 searches

were made in our online directory of local M.E. groups and specialist NHS services, helping people support local to them.

Our membership magazine *InterAction* keeps readers up to date with news and research, and is often described as a lifeline, particularly by those too ill to connect with the M.E. community online.



"I was diagnosed with M.E. in 2009. I found out about Action for M.E. through a meeting. I was needing help with getting DLA and I found them unbelievably helpful. I have over the years phoned them about various things and love to receive the *InterAction* magazine: it's like a comfort blanket, knowing someone is fighting our corner and who really cares."

Tilly, via email

Improving lives: we are there when no-one else is

Many people with M.E. feel overwhelmed by the scale of the challenge facing them. Action for M.E. is here to help, often when no-one else is. Our 2016 survey of our Supporting Members found that:

- almost two-thirds feel better supported
- more than nine out of 10 feel better informed as a result of being a supporter/lifelong member of Action for M.E.
- more than 75% feel a stronger sense of hope knowing that the charity is working with others to tackle important issues for people with M.E.
- 85% of our Supporting and Lifelong Members said they would refer a friend or family member to Action for M.E.

We offer an expert Welfare Advice and Support Service, with 98% of callers to this service saying that they feel more confident to progress their claim as a result.

Carole, commenting on Facebook, described it as "great advice given in a caring and supportive way, when we may be feeling frightened and daunted."



"Since my diagnosis, Action for M.E. has been a pillar of strength and support for me, advising me with work issues and signposting me to support groups and benefits. Although you may not have been able to physically do anything, having you there to talk to has been a huge help and relief in the past few months. Post-diagnosis, with all it entails emotionally, financially, personally – on top of symptoms – not having this service and people like you would have made my new world a very scary place."

Danni, via email

Improving lives: reducing isolation

M.E. can be a very lonely place. People with this complex condition may be too unwell to physically leave the house very often – or at all – while others have had to stop work and reduce social contact. Most tell us that they sometimes feel alone because their friends, family and colleagues don't fully understand the impact of M.E.

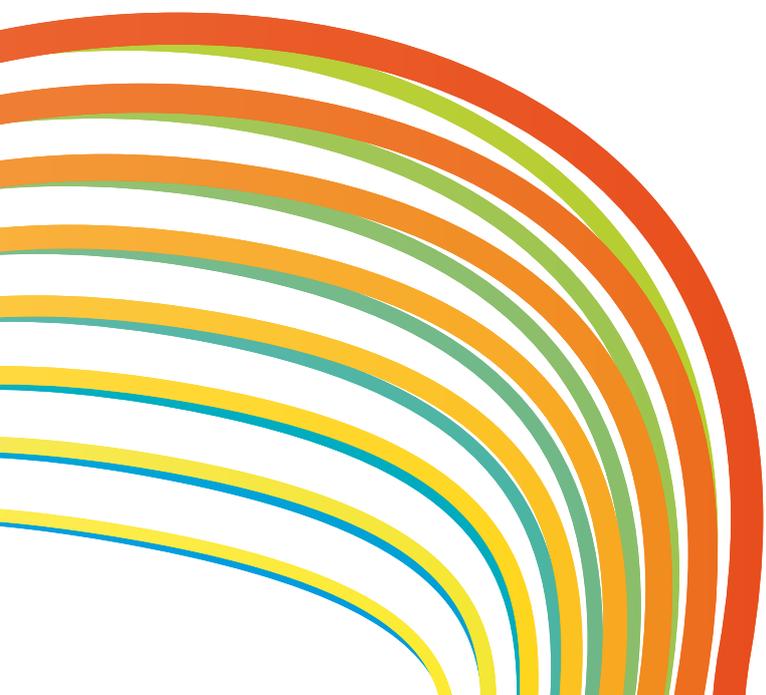
One in four people living with M.E. is house- and/or bed-bound. Some are so severely ill that they spend their lives in a darkened room, and cannot bear to be touched or hugged by a loved one. Our 2016 #dontignoreME campaign highlighted the isolation experienced by people with M.E., and shared tips and advice for reducing this.

Over the year, we sent out nearly 62,000 e-newsletters, keeping people with M.E. informed and helping them feel connected. And by continuing to offer a safe space via our M.E. Friends Online forum for people like Jubilee08 (below), we also support them to feel heard, and less isolated. This year, M.E. Friends Online was accessed on average more than 500 times a day, an increase of more than a third (36%) from the previous year.



"I'm two months into my diagnosis of CFS and have taken great comfort reading the forum. I am still very much at the 'coming to terms' stage. The learning curve has been immense and I'm still not fully understanding it all. For me, the constant nausea and being light-headed plague me every day – I am slowly learning about post-exertional malaise and what my limitations are. I presume this is something we slowly build our understanding of and how to manage this. Anyway, I really value the support the forum offers – it's good to be with people who 'get it'. Look forward to the continued support."

Jubilee08, via M.E. Friends Online



Inspiring action: raising awareness and understanding of M.E.

People with M.E. often tell us that one of the most draining things about having the illness is constantly having to explain what it is, and how it affects them. We raise awareness and understanding about M.E. and its impact and show that the stories of people with M.E. matter, helping make this hidden illness more visible. During M.E. Awareness Month, our stories, case studies, articles, letters

and interviews reached 3.5 million people in print, online and on the radio. Kirsty's was one such story – and the reaction she got came as something of a surprise.

"The response I've gotten from this is amazing," she emailed to say, after her story (below) appeared in her local newspaper. "I've got so many more people trying to understand

my illness and raise awareness, which is absolutely brilliant. I wasn't expecting all this. Thank you."

Over the year, we worked with journalists on stories that had a total circulation of nearly 5,758,000 and an advertising value equivalent (ie. what we would have had to pay if it hadn't been editorial) of nearly £180,000.

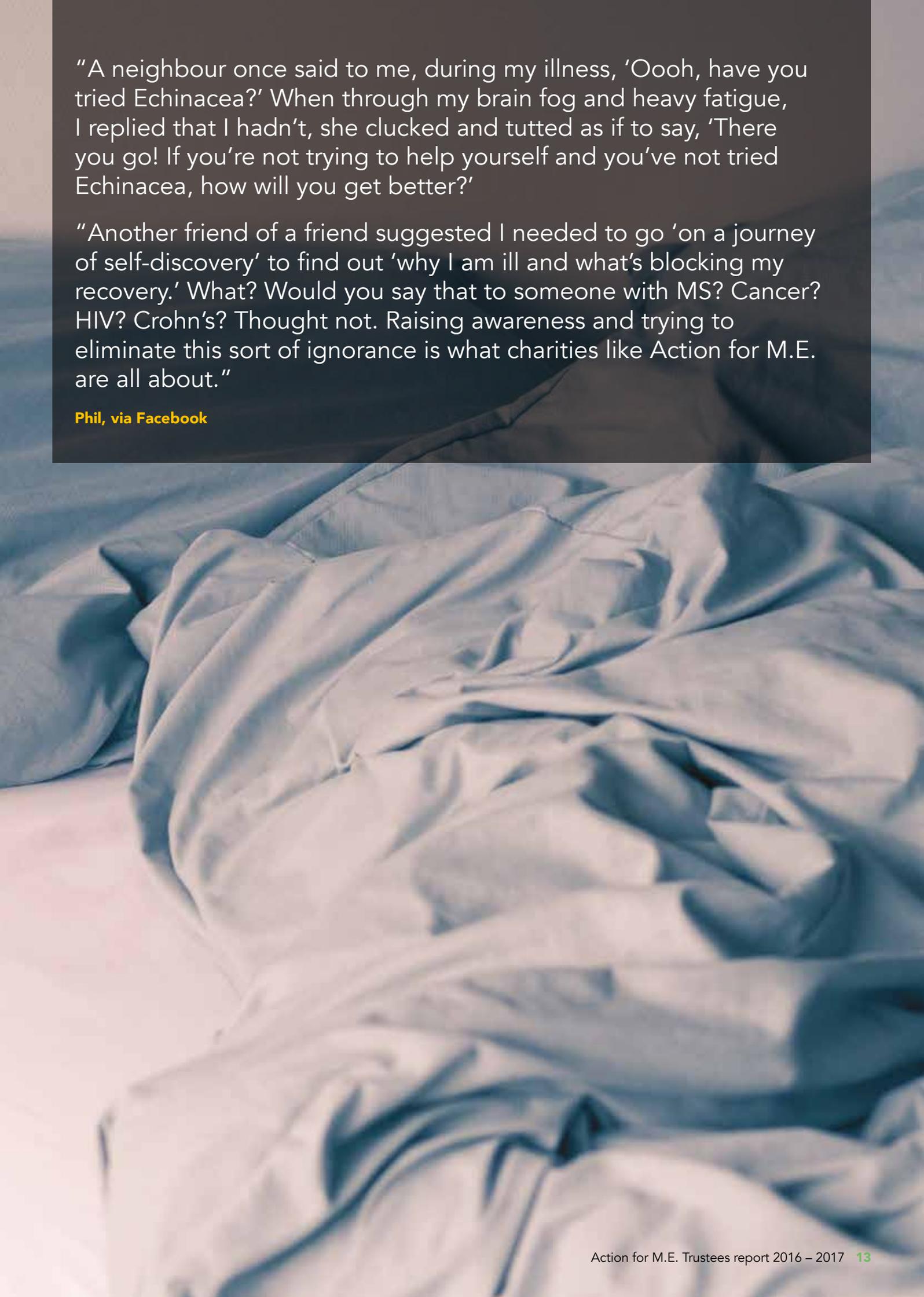


"I first became ill at the age of 15, but never got a diagnosis until the age of 20 which was made by a doctor at my local hospital. My most challenging symptoms would be the fatigue, headaches, muscle and joint pain; also my concentration and memory aren't great. These are with me most days, sometimes not so bad, sometimes very severe.

"I have been bed bound, though thankfully only on two occasions. The first time I was in bed for two weeks with a headache that was so bad I couldn't lift my head. I wouldn't wish that on my worst enemy. The second time was when I gave birth to my daughter; I had that little energy I couldn't even talk. I couldn't hold my daughter for almost two days. It was a horrible experience.

"I've lost a lot of friends, because they don't understand my illness or because I can't do things when I'm having a bad day. I still have a few friends that understand. I find it hard to actually explain how I'm feeling. Action for M.E. has helped by giving me a lot of information about M.E that doctors haven't. I've had to find things online and Action for M.E.'s website is one of the reliable ones."

Kirsty, Action for M.E. media case study



"A neighbour once said to me, during my illness, 'Oooh, have you tried Echinacea?' When through my brain fog and heavy fatigue, I replied that I hadn't, she clucked and tutted as if to say, 'There you go! If you're not trying to help yourself and you've not tried Echinacea, how will you get better?'

"Another friend of a friend suggested I needed to go 'on a journey of self-discovery' to find out 'why I am ill and what's blocking my recovery.' What? Would you say that to someone with MS? Cancer? HIV? Crohn's? Thought not. Raising awareness and trying to eliminate this sort of ignorance is what charities like Action for M.E. are all about."

Phil, via Facebook

Inspiring action: engaging with decision-makers

People with M.E. must have access to appropriate care and support that best meets their needs. But a lack of understanding about M.E. and its impact persists among those whose job it is to provide care and support for people with the condition. This not only includes those commissioning services but frontline health, social care and welfare benefit professionals, too.

One person who responded to our Green Paper consultation survey told us: "All the stress involved in the [welfare benefit] assessment/appeal process makes it extremely difficult to stay positive for months on end... an endless cycle of wasting all the energy I have on sceptical strangers trying to catch me out to save a bit of money that I'd rather be earning anyway."

Action for M.E. is taking important steps to ensure decision-makers are better informed about M.E. This year, we have highlighted the experiences of people with M.E., and asked professionals and decision-makers to work with us to improve outcomes, by:

- consulting with people affected by M.E. to inform our responses to the Government's Green Paper consultation on work and disability, the second independent review of Personal Independence Payment (PIP), the Work and Pensions Committee inquiry into PIP, and the Scottish Government consultation on implementation of devolved benefits
- sharing our SEE M.E. toolkit with Disability Employment Advisors at JobCentre Plus as part of our training session on M.E.
- accepting the Department for Work and Pension's Work and Health Unit invitation to convene a working group to explore potential policy changes and further actions to support employers to support those with long-term conditions
- meeting with GPs and primary care professionals at the RCGP's neurology conference, where they were keen to hear about how they could better support people with M.E., and enthusiastic about being able to access clinical expertise via our Webinars for GPs series
- launching our Inform M.E. Scotland project which, thanks to a £20,000 grant from the Scottish Government, will see us work with health boards, practitioners and people affected by M.E. to develop targeted educational resources for health and care professionals.



"As a fresh face to the Disability Employment Advisor role I gained valuable knowledge in the understanding of M.E. as there has been a lot of stigma around this debilitating illness. Having an understanding of M.E. will definitely help me, our work coaches and our claimants' journey into work. The toolkit is great, full of very useful contacts with clear steps and supporting tips. Definitely more awareness sessions on other illnesses would be very useful."

Disability Employment Advisor, JobCentre Plus

Investing in change: inspiring and supporting researchers

We support researchers to feel more inspired and better informed to solve the puzzle of M.E. Organising the third annual UK CFS/M.E. Research Collaborative (CMRC) conference in 2016 saw us bring more than 90 scientists, emerging researchers and people with M.E. together from around the world, including Canada, Australia and North America.

The CMRC's research-funding report, led by Action for M.E. Chief Executive Sonya Chowdhury and launched at the conference, shows that less than 1% of all active grants given by UK mainstream funding agencies goes to M.E./CFS research projects. You can read this report at www.actionforme.org.uk/2016fundingreport

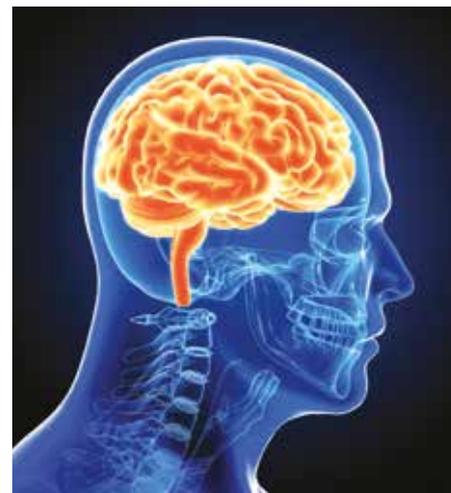
It is unacceptable that there is so little research investment into a condition that presents such a heavy burden on the lives of people with M.E. their children and families, and on wider society.

As an Executive Board member of the CMRC, we support it to provide a mechanism for M.E. charities, researchers and clinicians to work together in a coordinated and collaborative way; increase awareness of M.E. within the

research community; highlight priorities for research funding; and aim to increase funding for M.E. research.

We also have a practical part to play by investing in pilot projects to stimulate larger grant-funding. This year, we have continued to manage funds for research into the neurophysiology of pain in M.E., having accepted a donation of funds from the CFS Research Foundation for this work. Aiming to discover the physiological and chemical abnormalities underlying pain experienced by people with M.E., this three-year project will conclude in 2018.

Our research assessment process, developed to provide clarity and transparency, ensures that all applications we receive from researchers are scrutinised by our Scientific Advisory Panel (researchers with a proven track record in their field, ideally with a specialist interest in M.E.) and our Voice Committee (people with M.E., clinicians and allied health professionals). This ensures that people living with M.E. are an inherent part of decision-making about research projects that we do and don't fund.



“Experiencing top level, cutting-edge research has added greatly to my ideas and hypotheses on M.E. The networking opportunities provided by this event have been instrumental in identifying potential sponsors for a PhD project.”

**CMRC conference delegate,
2016**

This is just the beginning

The first year of our 2016 – 2021 strategy has seen us build a solid foundation on which to grow our reach and influence to improve more lives, inspire more action and invest in greater change. Immediately following the year end, Action for M.E. was thrilled to announce that the children's services

previously provided by UK charity the Association of Young People with M.E. (AYME) are now being offered by experienced staff and dedicated volunteers at Action for M.E.

This builds on AYME's considerable achievements over the past 20 years, changing the lives of tens

of thousands of children and their families. We will consult with young people and their families, and the professionals that support them, to design a service that that reduces isolation, increases knowledge and awareness, and ensures equality of care for children and young people with M.E.

Improving more lives

Over the next four years, we will support people with M.E. to enable them to better manage the illness, its symptoms and its impact by:

- facilitating a series of self-management webinars led by people with M.E. and professionals, empowering those affected by the condition to build on the techniques and strategies they use to cope with M.E. and its impact
- extending our telephone and email information and support service to reach 20% more children, families and adults affected by M.E.
- developing a model of support with, and for, local M.E. support groups to help them enhance their reach and reduce isolation for people with M.E. living in their local area
- working to secure funding for a pilot advocacy service to support people with M.E., particularly those severely affected, in accessing the services and care they so urgently need.

Inspiring more action

Over the next four years, we will work at local, national and international level to influence action in the UK to improve services and support for people with M.E. by:

- working with teachers, schools and children and family social workers to improve understanding of the impact of M.E. to reduce the number of child protection referrals experienced by families affected by M.E.
- ensuring that the voices and experiences of people with M.E. play an essential part in the revision of the National Institute of Health and Care Excellence guideline on M.E.
- undertaking a two-year pilot project to test the feasibility of securing a resolution on M.E. at the World Health Assembly Summit by 2021.

Investing in greater change

Over the next four years, we will play a leading role in bringing more money and more people into the field of M.E. research by:

- proactively supporting the UK CFS/M.E. Research Collaborative to build relationships with academics, industry and the patient community, including organising its annual conference
- fund at least one three-year postdoctoral or PhD studentship at any one time for projects focused on biomedical M.E. research.

Why your support matters

“M.E. arrived without warning after a particularly bad dose of the flu, though no one could tell me the exact cause or reason for it. It can happen to anyone; I was just unlucky to suddenly find myself with this illness that throws me completely off balance with a whole host of symptoms.”

Natalie became ill with M.E. in 2010. After accessing information and advice from Action for M.E. to help her manage its impact, she had a brilliant idea to help us reach more people who need our support.

Her Walk with M.E. project, launched in February 2017, asked people to walk one million steps in 100 days for people with M.E.

“Ten thousand steps per day is quite achievable for most but it’s a lot for someone like me,” says Natalie. “So people with M.E. taking part have been recruiting team members, to help out and donate their steps. That way I will be able to achieve my target of one million steps over 100 days.”

Three months later, 14 Walk with M.E. teams – including Action for M.E. staff members, Chief Executive Sonya Chowdhury and Senior Fundraiser Bella Whately – had raised £3,179 in sponsorship. These individuals are part of the 226-strong network of community fundraisers that supported us over the year, raising £102,070 in total.

Over the year, the support of trusts and foundations has contributed more than £191,190 to our vital work. This includes the continuing generosity of a family trust, who have supported Action for M.E. for 28 years, and who match-fund donations raised by people like Natalie, above, up to the value of £30,000.

We are lucky enough to have had support from individual donors who give through their trusts or directly, making a significant and positive difference to the lives of people affected by M.E.

As we move ahead with our 2016 – 2021 strategy, we are building relationships and offering inspiring opportunities, not only for philanthropists, but also companies and individuals who share our values of empathy, clarity, courage and collaboration.

We also know that the income we receive through legacy gifts is essential in enabling us to support generations to come. Leaving a gift to Action for M.E. in your will, however large or small, will help us make the stories of children, adults and families with M.E. matter to more people.

We ask our Supporting Members to give a minimum annual donation of £21 if they are able to – that’s around just 40p a week. Some give much more. All of them support our work because they believe, like we do, that people with M.E. matter.



“Action for M.E. is such a vital charity for anyone suffering with this condition. Just reading other people’s stories and sharing mine makes me realise that there are other people out there that suffer in the same way I do and who can offer support.

“I was diagnosed at the age of 13 by my GP following hundreds of tests, after all other possibilities were ruled out. At my worst, I couldn’t get out of bed and even walking to the kitchen for a drink was a huge struggle. It had such a huge impact on me as I was in my teens at the time. I lost contact with a lot of my friends, as many of them simply didn’t understand.

“Having a community of fellow sufferers through Action for M.E. was so important in making me feel more comfortable and less isolated in day-to-day life.”

Hannah, now 23, via email

How we raised and spent our money 2016-2017

Statement of financial activities

The results for the year have been significantly affected by the timing of legacy receipts. Last year we received exceptional legacies of £357,081 and during this year we were informed of further legacies of £145,365. However, this latter was not recognised in this year's accounts, due to the amount being uncertain at the year end, and therefore will only be recognised next year in accordance with the charity SORP and accounting standard FRS102 revenue recognition rules.

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 £681,687, down 33% on last year due to the inclusion of the exceptional legacy (and also the ending of our pilot employment support project).

However, excluding the effects of legacies, all other income was in fact down only 2.1%. With expenditure down by 9.2% at £741,134, the net result for the year was a deficit of £59,447. This resulted in unrestricted funds reducing by £34,692 to £398,369 (of which we have designated £85,000 for the launch of two new strategic projects in 2017 – 2018) and restricted funds reducing by £24,755 to £112,412.

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.

We are acutely aware that we have a significant responsibility as the largest of the UK M.E. charities, working with a tiny income in comparison to the scale of the challenge: 250,000 people with M.E. and the many more children, families, friends, employers and professionals affected by their illness. We will continue to work hard, with the generosity of our supporters, to strengthen our financial position and achieve the levels of income needed to deliver the promises we make to people 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 2016 – 2017, we raised £3.75 for every £1 invested in fundraising.

Balance sheet

The deficit generated from activities has decreased our accumulated funds and cash reserves at the year end. Unrestricted reserves have decreased primarily due to the timing of legacy income in the year and restricted reserves have decreased due to spend on research projects.

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

Reserves policy

The current policy is to maintain the level of 'free' 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 2017 reduced to £398,369, equating to 4.98 months at an average monthly spend rate of £80,000. This results in general funds standing at £313,369 after the allocation of £85,000 to designated funds. The Trustees agreed to designate funds, as set out in note 12 to the accounts, to achieve the ambitious objectives set out in our 2016 – 2021 strategy.

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

A resolution to appoint Moore Stephens as our new auditor for the ensuing year will be proposed at the 2017 Annual General Meeting.

Provision of information to Auditor

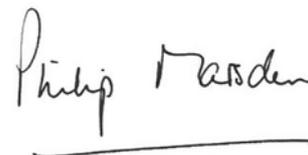
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish 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
10 November 2017.

Our people, structure and governance

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 re-election of existing Trustees. These results were subsequently confirmed at our annual general meeting in November 2016. 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 outside of 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.

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

Our work is hugely enriched because of our volunteers, who enable us to deliver extraordinary results given a small budget. In return, we support them to develop their skills and experience, celebrating their achievements and making sure they know they are valued members of our team.

During the past year, we have continued our strong history of volunteer involvement which added considerable value to our work. This includes a range of activities including working in the office, supporting our fundraising, communications and policy work, providing administrative support and contributing to *InterAction* magazine. The level of contribution made by volunteers varies from a couple of hours to a couple of days per week.

A range of medical, research and professional advisors also provide an invaluable network of support on a pro bono basis. To all of them, we would like to say a big thank you: we could not achieve what we do without you.

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.

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.

During 2016 – 2017, Trustees were satisfied that this was undertaken in a satisfactory manner. Given the financial situation of the charity, Trustees took a proactive role in supporting additional work in this area.

Related parties

Action for M.E. works collaboratively with other M.E. charities, influencing groups, health and social care professionals, government and senior officials and others to achieve its objectives. 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 increase our collaboration to build capacity and impact through the pursuit of common objectives. We also provide secretariat support to the CMRC (see p 15).



“Volunteering with Action for M.E. has helped me to come to terms with M.E., given me something to focus on and increased my self-esteem. It makes me feel like I can still use my skills and knowledge to contribute to a cause that’s really important to me. I want to combine my 28 years of living with illness, 11 years of healthcare education, and 10 years of pharmacy work, to train health professionals, improve our experience of health services, and help address the inequalities faced by people with M.E.”

Emily Beardall, pharmacist and Action for M.E. volunteer

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

We have audited the financial statements of Action for M.E. for the year ended 31 March 2017 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

This report is made solely to the charity's Trustees and members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and the Charities and Trustee Investment (Scotland) Act 2005. Our audit work has been undertaken so that we might state to the charity's Trustees and members 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 charity and the charity's Trustees and members as a body, for our audit work, for this report, or for the opinions we have formed.

Respective responsibilities of Trustees and auditors

As explained more fully in the statement of Trustees' responsibilities, the Trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair

view. We have been appointed as auditor under section 44(1)(c) of the Charities and Trustee Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts. Our responsibility is to audit and express an opinion on the financial statements in accordance with applicable law and International Standards on Auditing (UK and Ireland). Those standards require us to comply with the Financial Reporting Council's (FRC's) Ethical Standards for Auditors.

Scope of the audit of the financial statements

A description of the scope of an audit of financial statements is provided on the FRC's website at www.frc.org.uk/auditscopeukprivate

Opinion on financial statements

In our opinion the financial statements:

- give a true and fair view of the state of the charity's affairs as at 31 March 2017 and of the charity's incoming resources and application of resources, including the 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 and Trustee Investment (Scotland) Act 2005 and regulation 8 of the Charities Accounts (Scotland) Regulations 2006 (as amended)

Opinion on other matters prescribed by the Companies Act 2006

In our opinion 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 has been prepared in accordance with applicable legal requirements.

Based on our knowledge and understanding of the charity and its environment obtained during the course of the audit we have identified no material misstatements in the Trustees' report.

Matters on which we are required to report by exception

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

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



Paul Putnam
(senior statutory auditor)
For and on behalf of BDO LLP,
statutory auditor
Bristol, UK

11 November 2017

BDO LLP is a limited liability partnership registered in England and Wales (with registered number OC305127).

Action for M.E. statement of financial activities

Including income and expenditure account for the year ended 31 March 2017

| | Notes | Unrestricted funds (£) | Restricted funds (£) | Total 2017 (£) | Total 2016 (£) |
|--|-------|------------------------|----------------------|----------------|------------------|
| Incoming resources | | | | | |
| Incoming resources from generated funds: | | | | | |
| Voluntary income | 3 | 347,901 | 180,656 | 528,557 | 870,580 |
| Activities for generating funds | 3 | 19,569 | - | 19,569 | 8,251 |
| Investment income | 4 | 664 | 11 | 675 | 894 |
| Incoming resources from charitable activities | 3 | 101,217 | 31,669 | 132,886 | 133,313 |
| Total incoming resources | | 469,351 | 212,336 | 681,687 | 1,013,038 |
| Resources expended | | | | | |
| Costs of generating funds: | | | | | |
| Costs of generating voluntary income | 5 | 181,888 | - | 181,888 | 161,240 |
| Fundraising trading: costs of goods sold and other costs | | 3,420 | - | 3,420 | 3,049 |
| Charitable activities | 5 | 318,735 | 237,091 | 555,826 | 651,742 |
| Total resources expended | | 504,043 | 237,091 | 741,134 | 816,031 |
| Net movement in funds | 12 | (34,692) | (24,755) | (59,447) | 197,007 |
| Reconciliation of funds | | | | | |
| Fund balances at 1 April 2016 | | 433,061 | 137,167 | 570,228 | 373,221 |
| Fund balances at 31 March 2017 | | 398,369 | 112,412 | 510,781 | 570,228 |

All incoming resources and resources expended derive from continuing operations. The notes on p 27 to 37 form an integral part of these accounts.

Balance sheet

As at 31 March 2017 (company registered number 2906840)

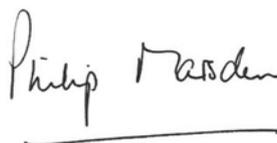
| | Notes | | 2017 (£) | 2016 (£) |
|--|-------|----------|----------|----------|
| Fixed assets | | | | |
| Tangible assets | 9 | | 4,396 | 5,938 |
| Current assets | | | | |
| Debtors | 10 | 32,360 | | 59,965 |
| Cash at bank and in hand | | 519,935 | | 594,410 |
| Total current assets | | 552,295 | | 654,375 |
| Creditors: amounts falling due within one year | 11 | (45,910) | | (90,085) |
| Net current assets | | | 506,385 | 564,290 |
| Total assets less current liabilities | | | 510,781 | 570,228 |
| Capital and reserves | | | | |
| Unrestricted funds: | | | | |
| General funds | 12 | | 313,369 | 433,061 |
| Designated funds | 12 | | 85,000 | - |
| | | | 398,369 | 433,061 |
| Restricted funds | 13 | | 112,412 | 137,167 |
| Accumulated funds | | | 510,781 | 570,228 |

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 27 to 37 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 10 November 2017

Action for M.E. cash flow statement for the year ended 31 March 2017

| | | 2017 | 2016 |
|--|------------------|-----------------|----------------|
| Net cash flow from operating activities | See note a below | (71,820) | 192,420 |
| Net cash flow from investing activities | See note b below | (2,655) | (908) |
| Net increase in cash and cash equivalents | | <u>(74,475)</u> | <u>191,512</u> |
| Cash and cash equivalents at beginning of period | | 594,410 | 402,898 |
| Cash and cash equivalents at end of period | | <u>519,935</u> | <u>594,410</u> |

Notes to the cash flow statement

a Cash flows from operating activities

| | £ | £ |
|---|-----------------|----------------|
| Net movement in funds | (59,447) | 197,007 |
| Depreciation | 4,872 | 5,033 |
| Financial income | (675) | (894) |
| | <u>(55,250)</u> | <u>201,146</u> |
| (Increase)/decrease in debtors | 27,605 | (18,998) |
| (Decrease)/increase in creditors | (44,175) | 10,272 |
| NET CASH FROM OPERATING ACTIVITIES | <u>(71,820)</u> | <u>192,420</u> |

b Cash flows from investing activities

| | £ | £ |
|---|----------------|--------------|
| Purchase of tangible fixed assets | (3,330) | (1,802) |
| Interest received | 675 | 894 |
| NET CASH FROM INVESTING ACTIVITIES | <u>(2,655)</u> | <u>(908)</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.

Information on the impact of first-time adoption of FRS 102 is given in note 19.

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 in previous years, small projects had an agreed 'in kind value' of £5,000. This financial period saw a single complex piece of work undertaken pro-bono by the firm. This was valued at £10,000.
- 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 2017 (£) | Total 2016 (£) |
|--|------------------------|-------------------------------|-----------------------------|------------------------|
| Voluntary income | | | | |
| Trusts and companies | 107,832 | 57,161 | 164,993 | 170,931 |
| Donations and appeals | 152,176 | 34,367 | 186,543 | 254,111 |
| Legacies | 39,805 | - | 39,805 | 357,081 |
| Tax recoverable | 38,088 | 3,344 | 41,432 | 27,555 |
| Gifts in kind | 10,000 | - | 10,000 | 35,000 |
| Grant Income | - | 85,784 | 85,784 | 25,902 |
| | 347,901 | 180,656 | 528,557 | 870,580 |
| Activities for generating funds | | | | |
| Lotteries and raffles | 11,874 | - | 11,874 | - |
| Christmas cards | 4,732 | - | 4,732 | 4,924 |
| Supplement commission | 2,670 | - | 2,670 | 3,010 |
| Merchandise | 61 | - | 61 | 317 |
| Other | 232 | - | 232 | - |
| | 19,569 | - | 19,569 | 8,251 |
| Incoming resources from charitable activities | | | | |
| Subscriptions | 96,659 | 370 | 97,029 | 103,075 |
| Conference fees | - | 31,299 | 31,299 | 27,940 |
| Charity journal | 3,024 | - | 3,024 | 2,107 |
| Information and publications | 1,534 | - | 1,534 | 191 |
| | 101,217 | 31,669 | 132,886 | 133,313 |
| | | Unrestricted funds (£) | Restricted funds (£) | Total funds (£) |
| 2016 Income breakdown | | | | |
| Voluntary income | | 699,935 | 170,645 | 870,580 |
| Activities for generating funds | | 8,251 | - | 8,251 |
| Investment income | | 894 | - | 894 |
| Charitable activities | | 133,313 | - | 133,313 |
| | | 842,393 | 170,645 | 1,013,038 |

4 Investment income

| | 2017 (£) | 2016 (£) |
|--|------------|------------|
| Interest from cash investments in the UK | 673 | 851 |
| Interest from Gift Aid and covenants | 2 | 43 |
| | 675 | 894 |

5 Resources expended

| | Unrestricted funds (£) | Restricted funds (£) | Total 2017 (£) | Total 2016 (£) |
|---|------------------------|----------------------|----------------|----------------|
| Costs of generating voluntary income | | | | |
| Staff costs | 96,304 | - | 96,304 | 91,357 |
| Direct fundraising costs | 36,977 | - | 36,977 | 21,745 |
| Support costs – see below | 48,607 | - | 48,607 | 48,138 |
| | 181,888 | - | 181,888 | 161,240 |
| | | | | |
| | Unrestricted funds (£) | Restricted funds (£) | Total 2017 (£) | Total 2016 (£) |
| Charitable activities | | | | |
| Communications and policy | 92,542 | - | 92,542 | 87,761 |
| Information and services | 219,249 | 103,395 | 322,644 | 382,310 |
| Research | 6,944 | 133,696 | 140,640 | 181,671 |
| | 318,735 | 237,091 | 555,826 | 651,742 |

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

| Activity | Activities undertaken directly | Support costs as below | Total (£) |
|---------------------------|--------------------------------|------------------------|----------------|
| Communications and policy | 82,126 | 10,416 | 92,542 |
| Information and services | 105,196 | 114,053 | 219,249 |
| Research | - | 6,944 | 6,944 |
| | 187,322 | 131,413 | 318,735 |

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 | 3,121 | 2,531 | 1,777 | 1,640 | 1,347 | 10,416 |
| Information and services | 34,179 | 27,711 | 19,455 | 17,958 | 14,750 | 114,053 |
| Research | 2,081 | 1,687 | 1,185 | 1,093 | 898 | 6,944 |
| | 39,381 | 31,929 | 22,417 | 20,691 | 16,995 | 131,413 |
| Fundraising | 14,567 | 11,810 | 8,291 | 7,653 | 6,286 | 48,607 |
| | 53,948 | 43,739 | 30,708 | 28,344 | 23,281 | 180,020 |

Governance costs include £10,000 (2016: £25,000) for professional services in kind.

| | 2017 (£) | 2016 (£) |
|---|---------------|----------|
| Governance costs | | |
| Administrative salaries - based on time spent | 14,663 | 8,766 |
| Indemnity insurance for Trustees | 1,407 | 1,109 |
| Governance training | 193 | 120 |
| Trustees' expenses | 2,426 | 274 |
| Meeting room hire and refreshment costs | 15,949 | 3,613 |
| Auditors' fees | 7,825 | 7,909 |
| Professional fees | 11,485 | 48 |
| | 53,948 | 21,839 |

All grants made by the charity during the year were related to research projects and were to institutions.

| | 2017 (£) | 2016 (£) |
|---|---------------|----------|
| Grant activities | | |
| Buckinghamshire New University – disease register | 6,882 | - |
| University of Newcastle – muscle dysfunction | - | 4,000 |
| University of Northumbria – immune responses | - | - |
| Queen Mary University London – brain in pain | 37,094 | 72,254 |
| University of Newcastle – mitochondrial DNA | - | 7,000 |
| University of Newcastle – autonomic dysfunction | 7,500 | 7,500 |
| | 51,476 | 90,754 |

This grant funding is included in research expenditure which also includes supports costs related to grant-making.

Total research expenditure for 2017: £140,640 (2016: £181,671), with total-less-grants-paid: £89,164 (2016: £90,917).

6 Net movement in funds

| | 2017 (£) | 2016 (£) |
|---------------------------------------|---------------|----------|
| This is stated after charging: | | |
| Operating lease | 24,219 | 24,219 |
| Depreciation of owned fixed assets | 4,872 | 5,033 |
| Auditor remuneration | 7,825 | 7,909 |
| Trustees' expenses | 2,426 | 275 |
| Pension costs | 8,419 | 4,935 |

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 2017 was £1,407 (in 2016 it was £1,109).

7 Staff costs and emoluments

| | 2017 (£) | 2016 (£) |
|--|----------------|----------------|
| Gross salaries | 383,124 | 358,723 |
| Employer's National Insurance | 27,391 | 32,734 |
| Pension contributions | 8,419 | 4,935 |
| | 418,934 | 396,392 |
| Numbers of full-time employees or full-time equivalents | | |
| | 2016-17 | 2015-16 |
| Engaged on charitable activities | 9 | 7 |
| Engaged in fundraising activities | 2 | 3 |
| Engaged on management and administration | 2 | 2 |
| | 13 | 12 |
| 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 £94,282 (2016: £88,232).

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

| | 2017 (£) | 2016 (£) |
|--|----------|----------|
| 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 six Trustees for travel and accommodation for the purpose of attending Board meetings. | 2,426 | 275 |
| Amounts of expenses incurred by Trustees that were donated back to the charity. | 1,435 | - |

9 Tangible fixed assets

| | Office equipment (£) |
|-------------------------|----------------------|
| Cost | |
| At 1 April 2016 | 52,074 |
| Additions for year | 3,330 |
| Disposals in year | (5,390) |
| At 31 March 2017 | 50,014 |
| Depreciation | |
| At 1 April 2016 | 46,136 |
| Charge for year | 4,872 |
| Disposals in year | (5,390) |
| At 31 March 2017 | 45,618 |
| Net book value | |
| At 31 March 2016 | 5,938 |
| At 31 March 2017 | 4,396 |

10 Debtors

| | 2017 (£) | 2016 (£) |
|------------------|---------------|---------------|
| Trade debtors | 311 | 16,878 |
| Prepaid expenses | 26,810 | 13,310 |
| Due from HMRC | 436 | - |
| Accrued income | 4,803 | 29,777 |
| | 32,360 | 59,965 |

11 Creditors: amounts falling due within one year

| | 2017 (£) | 2016 (£) |
|--|---------------|---------------|
| Trade creditors | 18,077 | 34,972 |
| Deferred income | 14,500 | 12,500 |
| Accrued Expenses | 10,625 | 25,982 |
| Unpaid pension contributions | 2,708 | 1,698 |
| Other taxation and social security costs | - | 14,709 |
| Due to HMRC | - | 224 |
| | 45,910 | 90,085 |

12 Funds

| | General funds (£) | Designated funds (£) | Total (£) |
|--|-------------------|----------------------|-----------------|
| Statement of unrestricted funds | | | |
| Balance at 1 April 2016 | 433,061 | - | 433,061 |
| Transfer between funds | (85,000) | 85,000 | - |
| Deficit for year | (34,692) | - | (34,692) |
| Balance at 31 March 2017 | 313,369 | 85,000 | 398,369 |

Designated funds include £130,000 set aside for an international advocacy project beginning in 2017 – 2018 and £30,000 towards an awareness raising campaign to combat the ignorance, injustice and neglect faced by people with M.E., to be spent in 2017 to coincide with the 30 year anniversary of Action for M.E.'s existence.

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

| | Tangible fixed assets (£) | Cash | Other Net current liabilities (£) | Total (£) |
|---|---------------------------|----------------|-----------------------------------|----------------|
| Analysis of net assets between funds -prior year | | | | |
| Unrestricted funds: | | | | |
| General funds | 5,938 | 457,243 | (30,120) | 433,061 |
| Designated funds | - | - | - | - |
| | 5,938 | 457,243 | (30,120) | 433,061 |
| Restricted funds | - | 137,167 | - | 137,167 |
| | 5,938 | 594,410 | (30,120) | 570,228 |

13 Restricted funds

| | Opening balances £ | Incoming resources £ | Outgoing resources £ | Closing Balances £ |
|--|-----------------------|-------------------------|-------------------------|-----------------------|
| Movements in restricted funds | | | | |
| Revenue restricted funds | | | | |
| Research | 123,110 | 85,793 | 133,697 | 75,206 |
| Living and learning with M.E. | 2,705 | (2,705) | - | - |
| Scotland services | 4 | 14,500 | 14,504 | - |
| Support, Empower and Employ people with M.E. | 10,636 | 31,045 | 41,681 | - |
| Peer mentoring | - | 63,703 | 47,147 | 16,556 |
| Improving support for care pathways | - | 20,000 | - | 20,000 |
| Hear M.E., influence M.E. | 712 | - | 62 | 650 |
| | 137,167 | 212,336 | 237,091 | 112,412 |

Research – donations are regularly received from donors wishing to see advances in research. Four pilot research studies have been supported in part from this fund during the year. See the grant activities table on p 31 for more details.

Living and learning with M.E. – this project offered opportunities for people affected by M.E. to come together to ensure that their voices are heard. Taking part in workshops, and collaborating on the production of a self-management resource, people with M.E. were supported to develop skills and reduce the significant isolation that often exists for people with the illness.

Scotland services – grant received from Scottish Government Health Directorate for our ongoing information and support service in Scotland.

Support, Empower and Employ people with M.E. – our 18-month pilot project offering specialist employment advice and support to people living in Bristol, North Somerset, Gloucestershire and South Gloucester who have a diagnosis of M.E.

Peer mentoring – funded by the Scottish Government and the 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 July, and are matching mentors with those who feel they would benefit from one-to-one mentoring support.

Improving care pathways – £20,000 received from Scottish government for project to begin in April 2017 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.

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 £2,708 (£1,698 in 2016) 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 2017(£) | Total Leases 2016(£) |
|--|-------------------------|-------------------------|
| Operating lease payments falling due: | | |
| within one year | 25,276 | 25,276 |
| within two to five years | 73,656 | 99,656 |
| over five years | - | - |
| | 98,932 | 124,932 |

16 Contingent assets

During the year the charity has been advised of a number of legacies and received significant amounts during the year.

Included in these were notifications of interests in residual estates, for which a practical estimation of the financial effect was not possible at the balance sheet date. The charity has subsequently received £145,365 in relation to these legacies.

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 £43,500 to be spent in the year to 31 March 2018 (£51,476 was spent in the year to 31 March 2017).

18 Post-balance sheet events

The charity undertook a merger with the Association of Young People with M.E. (AYME) on 3 April 2017 with a view to consolidating services provided by both charities and reducing duplication in the sector. By coming together in this way, we believe we can support more people, more effectively, and work more efficiently. We want to make sure that every penny raised to support children and adults affected by M.E. goes as far as it possibly can. We are confident that by delivering services in this way, we create better value for money, and be better able to secure additional resources to increase our work.

In addition, by supporting both children and adults, we can create more opportunities to raise the profile of M.E. and its impact, keeping the voices of people affected by M.E. at the heart of everything we do.

Following agreement to proceed from both charity's boards of trustees an appropriate set of Contract Termination and Novation letters were issued by AYME.

£17,915 cash transferred from AYME to Action for M.E. within two accounts, with some modest liabilities remaining, associated with AYME's closing down activities.

As of the staging date for the merger, six members of AYME's staff moved across to Action for M.E. following Transfer of Undertakings (Protection of Employment) regulations.

Following the staging date, work has been ongoing to support the close down and strike off for AYME as a company; business management and financial activities have all migrated to Action for M.E. and children's services has been established as an area of service delivery within Action for M.E.

19 Effect of first time adoption of FRS 102

The adoption of FRS 102 has necessarily altered the style and content of this report, including (but not limited to) the presentation of Operating Leases, analysis of net assets between funds, production of a cash flow statement and remuneration of key personnel.

Action for M.E. recognises that the changes to the reporting standards for U.K. charity are intended to promote greater transparency and accountability across the charity sector. There has been no impact on movement in funds, reserves or cash flows as a result of the transition.

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
Clare Francis MBE
Prof Anthony Pinching
Lord Puttnam CBE
Alan Cook CBE
(from 17 November 2016)

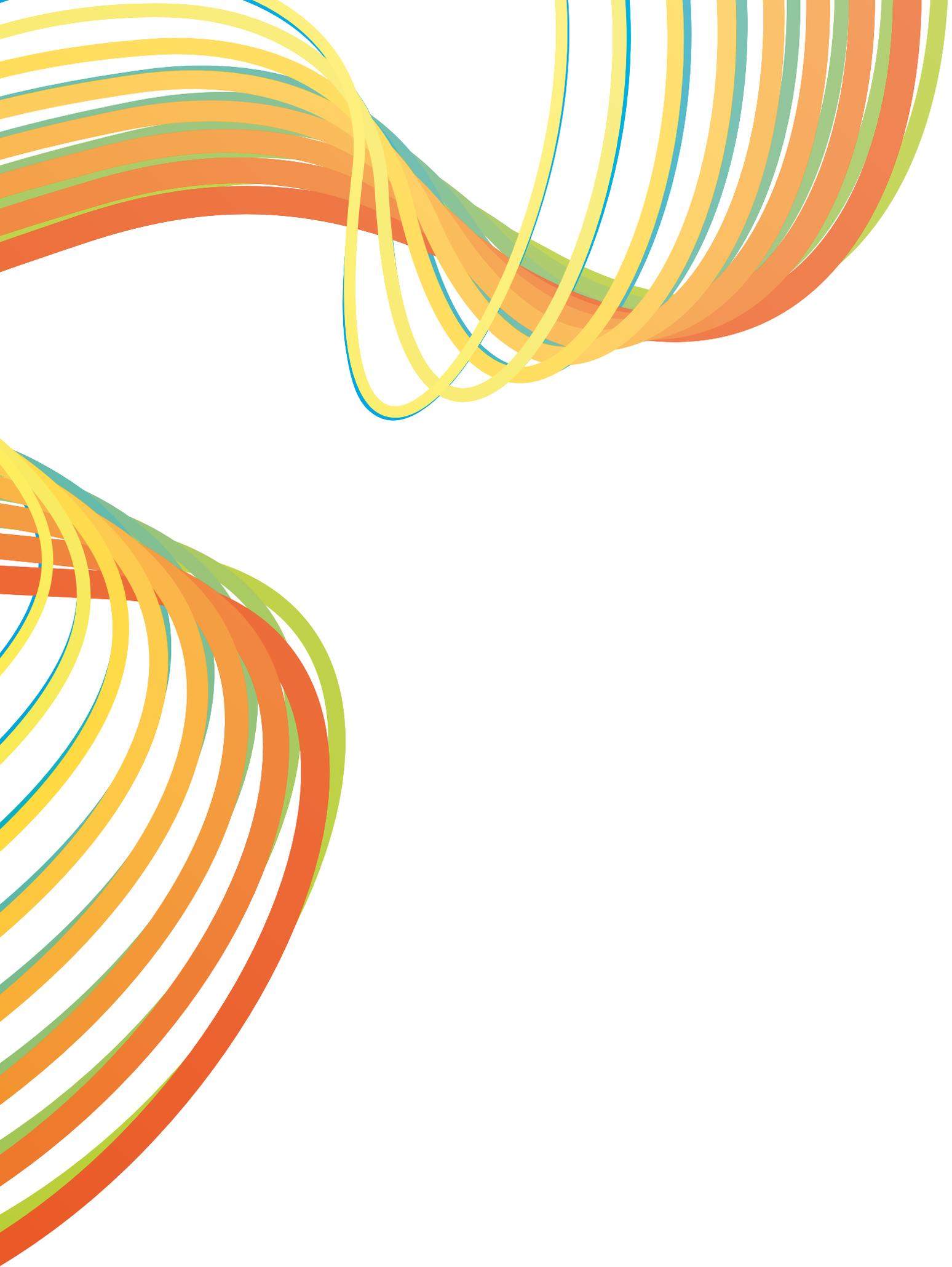
Trustees and Directors 2016-2017
Alan Cook CBE, Chair
(stood down 16 November 2016)
Jonah Grunsell, Chair
(elected 16 November 2016)
Philip Marsden, Treasurer
Katherine Thomas
Christopher J Cundy
Dr Gregor Purdie
Jane Logan
Jane Stacey
Jane Young
Ondine Upton
Sue Hardy
(elected 16 November 2016)
Gordon Berry
(elected 16 November 2016)

Chief Executive
Sonya Chowdhury

Principal Medical Advisers
Dr Gregor Purdie
Prof Julia Newton

Bankers
The Royal Bank of Scotland,
79-83 Colmore Row,
Birmingham B3 2AP

Auditor
BDO LLP, Bridgewater House,
Counterslip, Bristol BS1 6BX



“Action for M.E. is so helpful,
informative and uplifting; it is vital
for people with M.E. their friends
and families.”

Supporting Member, via our 2016 membership survey



42 Temple Street
Keynsham
BS31 1EH

Information and support: 0117 927 9551

Email: questions@actionforme.org.uk

www.actionforme.org.uk

Registered charity in England and Wales no. 1036419

Registered in Scotland no. SC040452

Company limited by guarantee, registered in England no. 2906840

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