

# More support, more action, more research

Action for M.E. Trustees' report  
2018 – 2019



Thanks to your support, we are here for children like Oliver



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**On the cover:** You might recognise Oliver, on the cover, from our 2017 – 2018 annual report, when he was too ill to attend school, and frequently bedbound. We have been supporting him and his family to access the care and support that Oliver needs. So we were delighted to receive an update from them in May 2019, along with the picture of Oliver at school in his wheelchair.

Oliver told us: "A consistent Teaching Assistant (TA) who understands has enabled me to attend school. Initially I went for just 20 minutes once a week and very, very gradually increased this. I can now do almost a full lesson, P3, as this is the best time of day for me and gives me time to

get ready to go and rest before my brother comes home. I use a wheelchair for school and avoid the busy, noisy times when classes are changing, going in before the class starts and leaving before it finishes. My TA stays with me; she helps with my co-ordination difficulties and reads/copies from the board for me. I am allowed to wear jog pants and a T-shirt; they are more comfortable and easier to manage as I can't fasten buttons very well. My home tuition had been just two days a week for 10 to 20 minutes. I can now do nearly an hour on Monday and Thursday, which is brilliant, though after my visit to school on Tuesday I find I can't concentrate or co-ordinate to do as much on Wednesday."



# What would you like to tell people about living with M.E.?

## “It sucks and everything is hard.”



Myalgic Encephalomyelitis (M.E.) is a serious systemic disease that steals lives. It is the most common cause of health-related long-term absence among school children;<sup>1</sup> and health-related quality of life for people with M.E. is much lower than for those with most other conditions including chronic renal failure, schizophrenia, and a number of cancers.<sup>2</sup>

More people have M.E. in the UK – at least 250,000 men, women and children – than those living with MS and Parkinson’s disease combined. Yet research into M.E. represents less than 1% of mainstream UK funding.<sup>3</sup>

M.E. is sometimes also diagnosed as chronic fatigue syndrome (CFS), or M.E./CFS – which may well be an umbrella term for a number of illnesses. We need biomedical research to better understand the different potential types of M.E. and/or CFS – and how to treat it more effectively.<sup>4</sup>

One in four children, young people and adults with M.E. are so severely affected they remain house- and/or bed-bound, in pain, often even unable to be hugged by their loved ones.<sup>5</sup>

While M.E. is more common in women and girls than it is in men and boys – a ratio of about four to one – it really doesn’t discriminate. M.E. can affect anyone, of any age or ethnic background, at any time.<sup>6</sup>

Healthcare, welfare benefits, productivity losses and unpaid informal care for people with M.E. costs the UK economy at least £3.3 billion a year.<sup>7</sup>

Less than half of NHS organisations (44%) told Action for M.E. that they commission a specialist service for M.E. Vast numbers of children and adults with M.E. do not have access to any specialist support.<sup>8</sup>

Lee, 14 (pictured), lives in Mid Glamorgan. He says: “Life before M.E. was fun. I could do normal things like go to school, play out with my friends, do sport and army cadets, have days out with my family, and go to theme parks.

“Now M.E. means I can’t go out, can’t go to school. I’m too tired to do anything. I find holidays and days out too much, so I don’t have them anymore.

“The toughest thing about living with M.E. is not being able to do sport or play football with my friends, or be outside. It sucks and everything is hard and annoying. My mum and dad help me cope, and my dog Max too.”

Lee’s mum Alana told us: “Lee struggles to leave the house. He has become quite isolated, and we struggle to spend time together doing nice things as a family. He also struggles with personal care and mobility.

“It’s not just being tired, it’s living with constant exhaustion, like having the flu for months without a break. He’s always worse after activity. Sleep reversal makes it hard to stick to a routine, or make any arrangements.

“The toughest thing is seeing how it affects him, how frail he looks, and not being able to do anything much to help him. M.E. has robbed us of our son and his teenage years, and his education.”

*How did we help Lee and his family? Find out on p 9 and 11.*

## Sonya Chowdhury's Chief Executive review

In 2018 – 2019, as we hit the halfway point in our 2016 – 2021 strategy, I look at what we have achieved as the largest M.E. support charity in the world. Working in partnership with many others, we are trailblazing for people with M.E.

In May 2018, we led the International Alliance for M.E. in hosting the first-ever M.E.-focused side event at the World Health Assembly in Geneva, raising understanding of M.E. among international policy-makers. In June 2018, having seen no national debates on M.E. for two decades, we co-published detailed briefings for the first of three parliamentary events this financial year.

Working collaboratively to influence key decision-makers in this way is essential in our mission to improve lives, with the current review of the National Institute of Health and Care Excellence (NICE) treatment guideline for M.E. offering huge potential. We continue to share and highlight

patient experience at every opportunity as part of this process; the new guideline is expected in October 2020.

Action for M.E. is the vanguard of essential information and support services, when people with M.E. need them most. In July 2018, we had funding confirmed from trusts and foundations, including the Henry Smith Charity, for our pilot regional advocacy service, something we've been trying to secure for a number of years. In November 2018, funding was confirmed to continue our brilliant Mentor M.E. peer-mentoring project. Both empower and support adults with M.E. to develop self-management skills, and take control of their care.

When parents are faced with professionals who tell them nothing can be done to help their child, it is easy to believe the worst. The expert support and advocacy offered by our Children and Young People's Service

is helping stop families – like Lee and Alana, whose story you can follow on pages 3, 9 and 11 – spiralling into crisis through lack of appropriate support.

All of this is made possible only by trusts, foundations, individual donors, Supporting Members, fundraisers and legacy givers whose generosity and determination ensures we reach ever more people with M.E. From my team, our Board of Trustees, and everyone we support, I say a huge thank you.



Sonya Chowdhury  
Chief Executive

## Jonah Grunsell's Chair report

Thanks to the generosity of our supporters, this is the second consecutive year that Action for M.E.'s income has passed the £1 million mark.

More than 12% of it was donated in just one week, to our Big Give Christmas Challenge 2018 campaign. Thanks to the support of our match-funders, including our champion, *Candis*, donations between £5 and £5,000 were doubled, and for the second year running, we raised the second highest total out of nearly 600 participating charities, many much bigger than we are. Every penny of that £142,500 total is helping us reach more children and adults with M.E., reduce more isolation, and invest more time and money in biomedical M.E. research.

Overall expenditure was £1,277,457, up 22% compared to last year, reflecting the continuation of our

international advocacy work (see p 10), and a greater investment in income generation. With a recorded total income of £1,112,958, we had a planned deficit of £164,499 in order to spend our additional income from the previous year most effectively, and bring our reserves back to an appropriate level.

I would like to join Sonya in extending my sincere thanks to the trusts, foundations, individual donors, Supporting Members, fundraisers and legacy givers whose generosity supports our work now, and for the future.

I am also hugely grateful to those of you who share our films on Facebook or Instagram, pass your copy of *InterAction* round your support group, retweet our stories and surveys, agree to speak to a journalist about your experience of M.E.,

contact your MP about our campaigns, or come to one of our events. The time, energy and trust you invest in us enables us to reach even more people with M.E. who need our support. Thank you.



Jonah Grunsell  
Chair, Board of Trustees

# Making progress

In July 2016, we launched our five-year strategy for change, embedded in our values of empathy, clarity, courage and collaboration. Since then, we've launched a new service for children and young people, and updated our strategy to reflect that.

Three years on, led by people with M.E. and in collaboration with others who share our goals, we have made encouraging progress, while always keeping in mind our strategic promise to "ensure that our organisation is as efficient and responsive as it can be."

## Improving lives

We promised to continue to offer an online forum for young people with M.E., enabling them to share information, peer-support and friendship, and feel less isolated. Responding to the needs of users, we launched a fresh Children and Young People's Forum on a new, user-friendly platform, supporting young people to be peer-support moderators.

## Inspiring action

We promised to work with local M.E. support groups to enhance, influence and increase understanding at a local level. As we have developed [Mentor M.E. across Scotland and our regional advocacy project](#), we have been exploring how we can work collaboratively with a number of groups, and share mutual support.

## Investing in change

We promised to undertake a five-year update consultation in 2018 – 2019 on the impact of the illness on health, welfare, education, employment and training. Recognising the potential of increased focus on M.E. during M.E. Awareness Month, we shifted our timetable to carefully plan and launch our consultation in May 2019, aiming to get 4,000 responses from children and adults with M.E.



# Some highlights from the year



## April 2018

Our amazing **London Marathon** runners Andrew, Jon, James, Jemma (pictured), Harry, Rob, Charlotte, David, Graham, Hayley, Lily, Martin, Andrew, Andy, Glen, Nick, Myurah and Rasha raise more than £35,000 to help us reach even more children, young people and adults with M.E.

## May

Around 9,000,000 readers have the chance to see what it's like to live with M.E. thanks to our **M.E. Awareness Month** press and media interviews, stories and case studies.

More than 1,860 people access information and support on our **Online M.E. Centre** every day this month.

Our brilliant **Walk with M.E.** teams raise £4,220 to support our vital work. "I have had to stop all my favourite hobbies and activities because of M.E. We haven't been able to do things as a family together. It's important to raise awareness and support Action for M.E. because it helps make people with M.E. know that people care about them." *Libby, 12, who took part in Walk with M.E.*



## June

We announce funding for two **biomedical PhDs**, led by Profs Chris Ponting (pictured) and Neil Harrison, looking at immunity and brain inflammation. "Just hearing that research is happening lifts me. This is what is needed on a day when my arms hurt just holding my tablet up to write this." *Comment from Glen on Facebook about our biomedical PhDs*

## July

Our **Ride London** fundraising total passes £4,220. Thanks team!

Funding is confirmed for our long-anticipated **pilot service to provide direct advocacy** to people with M.E. in the Midlands and South West. "Brilliant. I don't know how my son would manage without me to advocate for him, so it's reassuring this service is available should I not be able to someday. Thank you." *Louise, on Facebook*

## August

Our **fundraiser of the week**, Lizzie Carswell, raises £1,315 to support our vital work. Her sister Sheena has M.E. "I aim to run 365km by the end of November, marking Sheena's 365th day of being bed-bound. This personal challenge by no means matches the struggle she faces each day, but I am raising money with the hope that more research can help us work towards better treatment." *Fundraiser Lizzie*

## September

Martyn Kelk, whose daughter Alice was diagnosed with M.E. when she was 14, generously donates a month's sponsorship of **Notts County FC**. "I was extremely proud to be back at a place I used to love going, wearing my Action for M.E. Notts FC shirt. I hope that, by sharing M.E. in the match day programme, it helps to spread the awareness M.E. deserves and to showcase the amazing work Action for M.E. do." *Notts FC and Action for M.E. supporter, Sarah*



Researchers, clinicians and people with M.E. share experiences and ideas at the fifth **UK CFS/M.E. Research Collaborative (CMRC) conference**, organised by Action for M.E. "The standard of presentations and discussion throughout was higher than ever before... our best CMRC conference yet." *Prof Stephen Holgate CBE, FMedSci*

Our runners taking part in two big events this month – the **Great North Run and the British 10K** – raise more than £9,100. We could not do what we do without the support of people like them.



## October

Working with **Forward M.E.** – which marks ten years of campaigning and advocacy this month – we co-host a sold-out workshop and busy exhibition stand (pictured) at the **Royal College of GPs conference.** “There was a real buzz about the workshop. Lot of good pertinent questions at the end of the session and those that came seemed genuinely engaged.”  
*Dr Gregor Purdie, Action for M.E. Medical Advisor*

## November

The ALLIANCE confirms funding for our **Mentor M.E. project** to continue in its fourth and fifth year. “I dread to think where I would be without my mentor and the Action for M.E mentoring project. It’s such a simple idea that continues to have a huge positive impact on my life.” *Mentor M.E. mentee*



## December

Our second **Big Give Christmas Challenge campaign** – where donations are doubled thanks to a matching pot filled by some of our generous supporters – raises even more than our first, a whopping £142,500 in total.

We join 60 scientists, academics and organisations from 28 countries in supporting the **International Alliance for M.E.’s consensus document.** “We ask the World Health Organization to recognise M.E. as a “serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients (National Academy of Medicine, 2015).” *Recognition, research and respect: an agenda for change in M.E.*

We post the 1,720th card in the eighth year of our **Christmas Angels project**, which enables people with M.E. to share festive greetings and support via the Action for M.E. office.



## January 2019

The second and third parliamentary sessions on M.E. this year focus on diagnosis, treatment and research, in a **House of Commons debate, and Scottish Government Petitions Committee evidence session.** “I’d like to start by making a fundamental but important point to people living with M.E. in Scotland and that is I believe you. I believe that this disease is a limiting disease in terms of quality of life. I hear what you’re saying to us and your experiences matter to me.”  
*Scotland’s Health Secretary, Jeane Freeman (pictured)*

## February

We launch our **dedicated forum for children and young people** on a new platform, supporting young peer-support moderators to help keep it safe and fun. “There are so many great things about the forum, but the best thing for me is how it helps to keep away the feeling of isolation from the rest of the world. The fact that I can communicate with other people on here – who actually understand M.E. – really helps me feel less lonely.” *Young person’s forum user*

## March

Our brilliant **Bath Half Marathon** team raises more than £2,520. “Super proud of my son Tom who ran the Bath Half for Action for M.E. I was diagnosed with M.E. in 2014 and to say it has changed my life would be an understatement. Huge thank you to you all for raising money and, more importantly, awareness.”  
*Jo, on Facebook*



# “This could change my child’s life, because you have taken time to listen and encourage us to find answers.”

## Information and Support Service user, October 2018

Having the right information at the right time can make a crucial difference to those trying to find the best way to live with M.E. Children and adults with M.E. have told us how our Information and Support Service, and Welfare Advice and Support Service, make a real difference to their lives.

This year, our friendly and experienced advisors gave 1,325 information and support sessions by phone and email – more than five times every working day – and shared 1,365 copies of printed information that people with M.E. use to make informed decisions about the care, support and services they want and need to access.

Parents, like Alana (see opposite), dealing with inappropriate safeguarding referrals – or the threat of them – continue to rely on expert support from our Children and Young People’s Service. This includes

sharing up-to-date resources with the teachers, doctors and social care professionals working with the family, helping them offer the most appropriate support. In Scotland, families asked us to raise awareness of how M.E. affects children and young people. Our Educate M.E. steering group of parents from across Scotland co-produced new resources and training sessions for teachers, launched in May 2019.

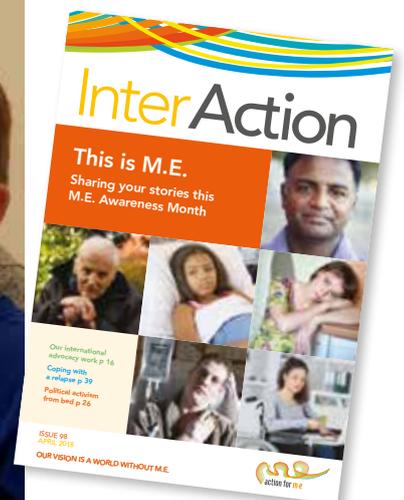
For the one in four people who are most severely affected, simply accessing and understanding information can be too much to manage. These vulnerable people need specialist advocacy, provided by trained advocates that understand M.E. and its impact. Thanks to some generous trusts and foundations, including the Henry Smith Charity, adults with M.E. in the Midlands and South West now have access to such a service.

We began setting up our regional advocacy service, also made possible thanks to a legacy of £80,000 in July, and we’re proud to now be able to offer advocacy information and support, empowering people with M.E. to access the services they need and deserve. One of our first clients told us: “You are extremely helpful and skilled. Your assistance and ongoing direction and support mean the world to me.”

In Scotland, people with M.E. have been connected with our services and support, thanks to our new links with local organisations, including Glasgow M.E./CFS Support Group and M.E. Highlands and Islands Network, working with us on our Mentor M.E. project to recruit and train mentors in the Highlands and Islands. These mentors will support others with M.E. to reduce isolation and increase their ability to self-manage.

“I was reading my *InterAction* magazine when my three-year-old grandson asked to see the pictures. He sat with me for ages, and we looked at every page together. Obviously, it’s never too early to educate people!”

**Supporting Member,  
Linda (pictured)**



## Three times more people are visiting our Online M.E. Centre for information and support

(an increase of 193% since April 2016); they view more pages, download more resources, and stay longer on our site.



Diagnosis and symptom management; welfare benefits support; and our peer-support forums, which **help children and adults with M.E. to connect, and feel less isolated**, are our most frequently accessed website pages and resources.

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“This whole process has been time-consuming and very daunting. I cannot thank Action for M.E. enough for your excellent service, both verbally and through comprehensive factsheets that I was able to download. **It was of huge benefit to know that we were not alone**”.

**Welfare Advice and Support Service user Lorraine**

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## Twitter users interacted with and shared our content 45% more than last year,

connecting not just with us but also each other.



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“It can be very lonely coping with chronic health problems, and dealing with benefit claims adds extra stress to an already distressing situation, especially when there is no help available locally. **Action for M.E. is a valuable resource** and it's reassuring to know that there are wonderful people like you who care and are doing as much as they can to help others.”

**Elaine, who called us for support**

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## Lee's story continued

Lee is a member of our Children and Young People's Community. Led by him and his family, we have been supporting them to better understand what's happening to Lee, sharing options and ideas that they can consider using to help them cope with the impact of M.E.

“Lee has asked me to thank you on his behalf for visiting and for understanding him, but also for all your help and support in helping all of us understand M.E better. Both me and my husband want to thank you for the clarification on where Lee sits within the diagnosis, how and what to ask for from his healthcare professionals, and what we need to be recording in diaries for healthcare professionals. Mary-Jane [Willows, Head of our Children and Young People's Service] helped us find Lee's baseline, helped us put together a management plan, and with pacing, which has worked really, really well – much better than what we were getting prior to working with Action for M.E.”

*Alana, Lee's mum*

# *“Forward M.E. is a great example of the power of organisations like Action for M.E. working together for the same cause.”*

## Action for M.E. supporter Glen, commenting on Forward M.E.’s 10th anniversary

Children and adults with M.E. still face ignorance and injustice from those who don’t understand its impact. At the very least this leads to isolation and stigma. For those put under pressure to do too much, to return to school or work too soon, the consequences can be devastating.

That’s why the work we do to raise awareness and increase understanding of M.E., and influence planners, practitioners and policy-makers, is so important.

In 2018 – 2019 we had detailed conversations with more than 30 MPs and MSPs, equipping them with the information and resources they need

to fight for their constituents with M.E. Nineteen people with M.E. used our personalised briefings to engage with their MP about the issues having a direct impact on their lives. Our Welfare Rights Adviser led an M.E. training session for 125 DWP Work Coaches, and we ensured that the voices and experiences of people with M.E. were included in a debate on welfare, specifically Universal Credit, in March.

Working collaboratively with those who share our values and goals means we can achieve so much more.

As Chair of the International Alliance for M.E. (IAFME), we led #MillionsMissing event outside the

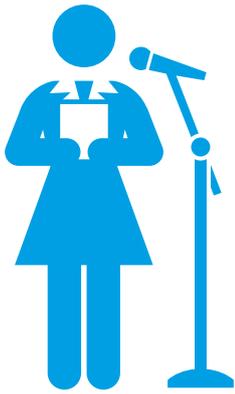
UN headquarters in Geneva on M.E. Awareness Day; and highlighted the need for accelerated biomedical research, and medical education, at the first-ever World Health Assembly side event focused on M.E.

We are an active member of the Health Conditions in Schools Alliance, meeting with the Minister for Children and Families and Ofsted to ask for action on enforcing regulations on medical conditions policies in schools.

And we help drive Forward M.E., a collection of charities led by the indomitable Countess of Mar, which saw its 10th anniversary this year.

- GPs crammed into Forward M.E.’s standing-room-only workshop on diagnosis, treatment and management at the Royal College of GPs conference in October; we will return to this event in 2019.
- Parliamentary debates on M.E., led by Carol Monaghan MP and pushed for and promoted by Forward M.E., took place in June and January; we supported people with M.E. to engage with their MPs.
- More than 2,270 people with M.E. were able to share their experiences of treatment and symptom management with the NICE Guideline Development Committee, via the detailed Forward M.E. survey we led on.





## Nearly 60 MPs, Lords and MSPs spoke up for people with M.E.

at two parliamentary debates and an evidence session in Westminster Hall, the Commons Chamber and Holyrood.



### "This sort of thing is so important.

When I was looking for work after my diagnosis, I could not get them to understand there were some jobs and shifts I could not do. I wanted to work so badly, and in the end had to take a job that made me much worse. Keep up the good work, Action for M.E."

Rebecca, commenting on Facebook on our training for DWP Work Coaches



## "There are more pandas in Scotland than M.E. nurses"

was the year's most memorable headline, from media coverage (with a reach of 1,500,000) of *This is M.E.*, our 2018 M.E. Awareness Month Scottish Parliament event.



It really brought to life the finer details of what it is like to live with a chronic condition. **The knowledge we gained from Action for M.E. was an essential starting point in informing our work with people who have M.E.**"

Advocacy worker who liaised with our Regional Advocacy Support Service team



### More than 60 clinicians, researchers, and organisations from 28 different countries

supported IAFME's consensus document, *Recognition, research and respect: An agenda for change in M.E.*

## Lee's story continued

"Lee was diagnosed in December 2018, having had symptoms since May. The challenge we face as a family is the lack of knowledge and understanding from everybody that we deal with. Treatment was... I can't even describe it, it was horrendous... not knowing what to do when he crashes, not getting any education, being pulled in for meetings about attendance, and feeling very lost and frustrated.

"Mary-Jane [Willows, Head of our Children and Young People's Service] attended a multi-disciplinary team meeting, and she liaises with the school quite regularly with advice and guidance on how they can best support Lee. Now we feel a bit more positive moving forward, and that we're not going to have a lot of the negativity that we've had, like 'Lee has to want to get better.' He doesn't want to feel this way.

"Anything I can do to help raise awareness, just let me know. Mary-Jane has been a massive support and fought Lee's corner. She has given him a voice and us the capacity to understand what he is going through."

Alana, Lee's mum

### Around 9,000,000 readers had the chance to learn more about M.E.

in our M.E. Awareness Month interviews, stories and case studies in *The Sunday Times*, *Metro*, *Sky News online*, *BBC Radio London*, *Candis* and others, with an advertising value equivalent of £340,000.

# ***“We will share data with other research groups to ensure more rapid progress in biomedical M.E. research.”***

**Prof Neil Harrison, on brain inflammation research funded by Action for M.E.**

How does the brain’s reaction to inflammation contribute to the symptoms of post-exertional malaise, fatigue and pain? How do the immune cells of people with M.E. compare with those from healthy people?

We hope to answer these questions by funding two biomedical PhD studentships, adding to knowledge that’s moving us towards improved diagnosis, more effective treatments and, one day, a cure.

Student Marisa Amato, supervised by Prof Neil Harrison (pictured below) at the Brighton and Sussex Medical School, who match-funded our investment (total project cost £92,000), will test the hypothesis that people with M.E. show increased immune responses to very mild

inflammatory triggers. The aim is to understand whether this “overactivates” the brain system responsible for encoding the body’s internal physiology, leading to symptoms like post-exertional malaise.

Co-funded by the Scottish Government’s Chief Scientist’s Office (total project cost £90,000) and supervised by Prof Chris Ponting at the University of Edinburgh, student Joshua Dibble will test immune cell samples from the UK M.E. Biobank co-founded by Action for M.E., checking for any ongoing response to infection or autoimmunity.

“I have several family members who have experienced M.E.,” Joshua says. “After completing my Masters degree in Mathematics and

Theoretical Physics, I decided to refocus my academic work into a more applicable area. Since I had a significant amount of computational experience from my undergraduate studies, I switched into genetics and bioinformatics, specifically to work on this project. As M.E. is so poorly understood, I hope my contribution will at some point help the many people with this illness around the world.”

Joshua and Marisa were among the 100 people living with M.E., scientists, clinicians and industry experts from six countries who shared insight and expertise at the fifth UK CFS/M.E. Research Collaborative (CMRC) conference. One delegate told us it felt “hugely valuable in understanding current research” and was a “fantastic opportunity for researchers, charities, patients and carers to have a collective voice, share knowledge and agree priorities to move forward.”

As a CMRC Board member, we not only take the lead in promoting and organising this event, but also provide the secretariat for this essential collaborative. Our films of presentations by 15 researchers have been viewed more than 5,000 times, and our live tweets over the two days were liked, re-tweeted and replied to more than 5,200 times – that’s once every 10 seconds.

As a result of workshops held at the conference, the CMRC has set up four working groups focusing on ‘omics and big data; immunology; mitochondrial biology; and medical education, who are already engaging with medical schools about their training on M.E.



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“I wanted to offer you my personal thanks for all the effort and dedication your team put into making our fifth CMRC conference such a success. **It helped greatly in bringing together the researchers, patients and carers in a unique way which was particularly evident in the Research Priorities workshop.** I know we have much to do, but meetings like we have just experienced gives one the energy to keep moving forward.”

**Prof Stephen Holgate CBE, FMedSci**

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PhD student Joshua Dibble, co-funded by Action for M.E. and the Scottish Government Chief Scientists Office at the University of Edinburgh will analyse the results of

## experimental work on 160 samples from the CureME Biobank

divided equally among mild/moderate and severe M.E. cases, multiple sclerosis disease controls, and healthy controls.

### Investing in children's futures

As well as investing in research, we invest time, money and resources in the futures of children and young people with M.E. We support young volunteers to develop skills as volunteer peer-moderators for their Young People's Forum, and as contributors to their regular *Cheers* e-newsletter (featuring *Cheers* mascot Beartholomew, pictured).

“Children who contribute and have their articles published are very excited to see them,” says Helen Jackson, volunteer *Cheers* Editor. “Their illness can prevent them achieving much and this is something they can do.”



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“By investigating many cells from many people, **our research could help us stratify M.E./CFS into different sub-groups**, which in turn could help with targeting treatments more effectively.”

**Prof Chris Ponting (pictured with Sonya Chowdury), on the immune cell research we are co-funding**



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“As a severe M.E. sufferer, thank you so much. **These are the questions we so desperately need answers to.**”

**Mandy on Facebook, commenting on news of our biomedical PhD funding**

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# Your support makes our work possible

For the second year running, we were blown away by the generosity of all of you who supported our Big Give Christmas Challenge. This fantastic campaign means that your donations were doubled, thanks to match-funding from major donors and our Big Give Champion, Candis. For our 2018 campaign, we asked you to share our campaign with a friend – and see their donation doubled too. The result took us by surprise: £142,500.

**69%**

more donations than last year

[theBigGive.org.uk](http://theBigGive.org.uk)



More than 300 online donations in just seven days totalled

**£126,857**

For the second year in a row, **we raised the second highest total out of nearly 600 participating charities**, including some much larger than us.



Including gifts by post and phone, the grand total came to

**£142,500**

So many of you make gifts that power our work forward. We are especially grateful to those who support us every year, enabling us to plan for the future with your annual gifts, direct debits, Supporting Memberships (a minimum of £21 a year) and to the handful of you who give us five-figure sums every year.

Gifts left to us in wills help us reach even more children, young people and adults with M.E. This year, we received legacies of £97,039 in total,

helping us change more lives, raise more awareness and increase understanding of M.E.

Nearly a quarter of our income (23%) in 2018 – 2019 came from generous charitable trusts, ensuring our services and support are there when people with M.E. need them most. After helping launch our Children and Young People's Service, the Robert McAlpine Foundation has continued as its key funder. The Draper's Charitable Fund helps our

M.E. Friends Online peer-support forum continue to grow. Other dedicated funders whose generosity over the years allows us to continue to support children and adults with M.E. include The John Swire 1989 Charitable Trust, The De Laszlo Foundation and The Garfield Weston Foundation, along with regional trusts who ensure we can provide support across the UK, including the Sir James Reckitt Charity in Hull and East Yorkshire.



Devonshire House Preparatory School held a film night for Action for M.E. in July 2018. Students organised two movies to be shown at the school and ran a busy tuck shop, raising £584 for Action for M.E.

Nick West has been a collector since 1975, when he was gifted a book about beers from his wife. He has since amassed a collection of more than 9,300 British beer cans. He has told us that, "after 42 years of collecting, my wife finally had enough and I've spent the last 18 months selling most of my collection to other collectors all around the world. I've donated the remaining cans to Oakham Treasures in Portbury. Keith Sherrell, the owner, offered me payment, but I asked him for a donation to charity instead. Because of my family connections to your organisation we agreed that should be Action for M.E."



Our amazing community fundraisers bring in £1 in every ten – and many see their gifts matched by a generous family trust, making their efforts go twice as far. You run the London Marathon, Great North Run, British 10K, and Bath Half; you cycle Ride London and don parachutes for skydives (this year, more of you took bond places in these events overall than in the past three years together).

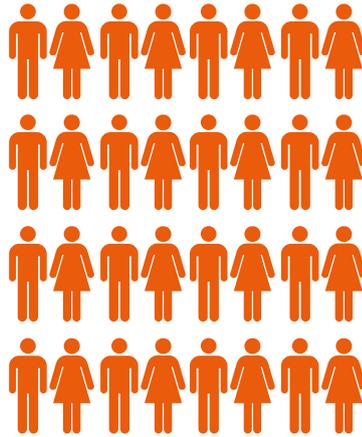
You donate month in, month out, through payroll giving. You have craft sales and sponsored silences; you join Dog Jogs and nature walks, host pub quizzes and fun days, raffles and bake-offs. You take part in our Walk with M.E. fundraiser, with each team walking one million steps in one hundred days – and sharing the steps out between teams, so friends and family members with M.E. only walk what they can walk, even if that's no steps at all.

**For all who use your valuable time and energy to support us, and to those who sponsor you and cheer you on, from the sidelines or from bed, we say a huge and grateful thank you.**



**£49,802**

raised by bakers and crafters, and other community fundraisers



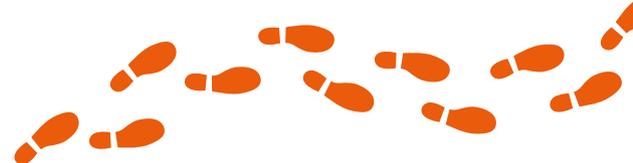
**£5,566**

raised by payroll givers



**£45,245**

raised by runners, cyclists, trekkers and skydivers



**£4,220**

raised by our 16 Walk with M.E. teams



Renée undertook a sponsored walk for us, raising £611. For many with M.E., this level of activity would simply not be possible. For Renée, careful planning was essential to ensure she did not push herself beyond her limit. "To function, and live life enjoyably, I have to plan, plan, plan and sometimes say no to things or cancel, to ensure my body will be able to cope with day-to-day life," she explained. "I wanted to give special thanks to a charity who were so supportive and engaging through all these years I first struggled with it. From being able to access resources to sending me birthday cards every year, they always reached out to me and made me feel that I was not alone in this."



Eleven-year-old Rebecca was diagnosed with M.E. in 2016. "One of my hobbies is beading and I love making earrings, so I decided to sell them to raise money," she says.

"I feel really sore and tired lots of the time, but I know that there are people with it who struggle much more than me, so I wanted to try and do something for them." So far she has raised more than £480 for Action for M.E.

# What next? More support, more action, more research

With two years left of our current strategy, our dedicated Board of Trustees, our creative and committed staff team, and our enthusiastic volunteers continue to work together, and with others who share our goals, to fulfil the promises we have made to people with M.E.

**In May 2019, just after year-end, we launched our Big Survey, asking children, young people and adults to tell us about the impact of M.E. on the lives of them and their families,** and their experiences of diagnosis, symptom management, access to health and social care, and coping with work and/or school.

The insight and experiences shared by more than 4,000 Big Survey respondents is helping us develop our services offering targeted

information, improved support and peer-support to reduce isolation. It's also shaping the work we're doing to increase understanding of M.E. and its impact among professionals and policy-makers, asking them to take action to improve the lives of children, young people and adults with M.E.

You can find out more at [www.actionforme.org.uk/news](http://www.actionforme.org.uk/news) and on our social media channels @actionforme, or come along to one of our events, like our annual conference and AGM in London each autumn.

We also use ongoing feedback from our services, stakeholders and online communities, and their responses to smaller consultations on specific issues, to drive what we do.

In response to challenges faced in delivering a consistent, stand-alone Welfare Benefits Service, we have undertaken work to improve the support we can offer as part of our very busy Information and Support Service. **Our new Information, Support and Welfare Service has more capacity and resources** to support those who need it, offering welfare benefits advice (accounting for around a third of calls/emails to our service this year) alongside support for most other aspects of living with M.E.

Accessing healthcare and appropriate symptom management is a critical issue for people with M.E. **The full-scale review of the NICE guideline for M.E. offers the potential to change the treatment landscape in the UK.** This will require significant input from advocates and charities like Action for M.E., to ensure the guideline reflects the highest-quality evidence available, led by patient experience.

As well as funding biomedical PhDs (see p 12), we promised to invest in change through our new **Clare Francis Fellowship, supporting talented researchers to build an independent research career** and increase the skills and expertise in the field of biomedical M.E. research. We anticipate being ready to launch this next year. Watch this space!



“

*“If I’m not in my wheelchair, people don’t think I have a disability. If I am in the wheelchair, people treat me as though I’m invisible. The ironic thing about this disorder being called M.E. is that I’ve lost me. We need change.”*

Voice from our Big Survey

”

# How we raised and spent our income this year

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

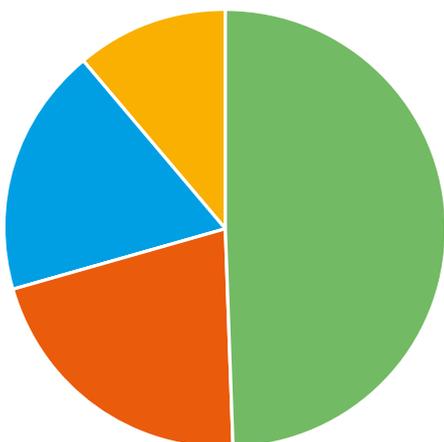
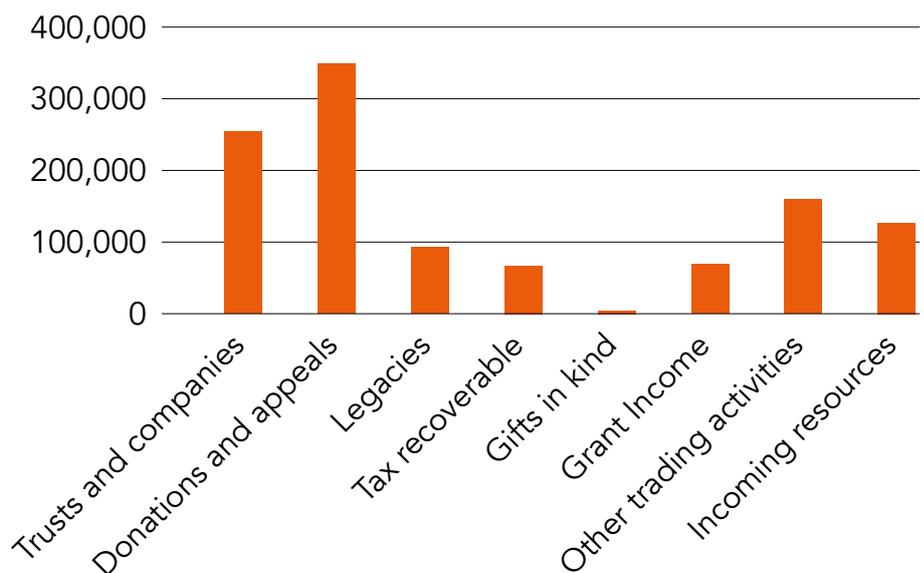
More than three-quarters (79%) of what we spend is on our information and support services, our campaigning and influencing work, and our investment in collaborative biomedical research, collectively known as our **charitable activities**. To do these activities effectively, we need **committed and dedicated staff** who bring the right skills, knowledge and experience to every area of our work. That's why half (49%) of our total gross expenditure is on staff salaries (including employer National Insurance and pension contribution).



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

**During 2018 – 2019, we raised £4.20 for every £1 invested in fundraising.**

In our strategy, we promise to continue to strengthen our financial position and achieve the levels of income and efficiency we need to deliver the promises we make to people affected by M.E. Our **recorded total income** for the year was £1,112,958, the second consecutive year that our income has surpassed £1 million.



**Overall expenditure** was £1,277,457, up 22%, reflecting the continuation of our international advocacy programme, and a greater investment in income generation. The net result is an overall deficit of £164,499, as planned by the Trustees. This enabled us to spend our unexpected additional income from the previous year while bringing our unrestricted reserves back to within our policy level of three to five months of unrestricted operating costs.

## **This year, we spent:**

£633,821 on our information and support services

£269,633 on fundraising (cost of generating voluntary income at £264,972 plus goods and trading at £4,661)

£233,220 on our campaigning and influencing work

£140,783 on our investment in collaborative biomedical research

# Statement of financial activities

We are the largest UK charity for people with M.E. – and the only one that supports both children and adults. Nevertheless, our resources, capacity and (full-time equivalent) staff team of just 19 seem tiny when you consider the critical and often complex needs of 250,000 men, women and children in the UK living with M.E., and the loved ones and professionals who support them. In order to deliver our promises to them, and with vital support from our donors and supporters, we continue to strengthen our financial position and bring in the income we need to tackle the ignorance, injustice and neglect they face every day.

## Our income and expenditure

Taking the above into consideration, Action for M.E. has achieved a sound underlying financial performance for the fourth year running. Our recorded total income was £1,112,958, with this being the second consecutive year that our income surpassed £1 million. There are no contingent assets to report for the financial year 2018 – 2019. Starting the year with additional reserves, due to unexpected additional income including a generous legacy, the Trustees agreed a planned deficit budget in order to make the best possible use of funds donated to the charity.

Overall expenditure was £1,277,457, which is up 22%, reflecting the continuation of our international advocacy programme, and a greater investment in income generation. The net result is an overall deficit of £164,499. At the year end, unrestricted reserves were £363,744 (down £135,509). Please see information below under 'Reserves policy.'

Restricted reserves were £204,459 (down £28,990) of which £75,333 will be expended over the course of the next year on our two biomedical PhDs and research fellowship. We continue to monitor our level of reserves to ensure we can maximise the work we do while ensuring the charity has a strong medium-term financial position.

We aim to raise £3 to £5 for every pound we spend on fundraising, growing our income streams to increase the amount we can spend delivering our services and support. During 2018 – 2019, we raised £4.20 for every £1 invested in fundraising.

## Balance sheet

The planned deficit budget for this financial year was realised, and has decreased our accumulated funds and cash reserves at the year end. Unrestricted reserves have decreased primarily due to planned investment in our new regional advocacy service (see p 8) and ongoing investment in our international advocacy work in Geneva (see p 10).

## Funding sources

The principal funding sources for Action for M.E. are charitable trusts, legacy giving, community fundraising and events, Supporting Membership income, and individual gifts. Other funding sources include National Lottery Community Fund, Scottish Government grants, Gift Aid, 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' (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 2019 decreased to £363,744, equating to 4.7 months at an average monthly spend rate of £76,000 within unrestricted funds.

The Trustees decided to transfer back to unrestricted funds the £128,752 of designated funds remaining at the year end (see p 35), to provide more flexibility for the future.

## Grant-making policy

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

## Statement of Trustees' responsibilities

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

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

In preparing those financial statements the Trustees are required to:

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

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

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

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

## Auditor

Moore Stephens was appointed as our auditor at the 2018 Annual General Meeting.

## Provision of information to Auditor

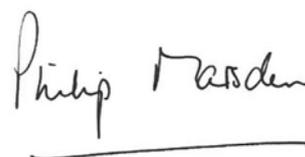
So far as each of the Trustees is aware at the time the report is approved, there is no relevant audit information of which the company's auditor is unaware, and the Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish 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 Thursday 26 September 2019

# Our people, structure and governance

## Public benefit

The Trustees confirm that they have complied with the duty in the Charities Act 2011 to have due regard to public benefit guidance published by the Charity Commission. The annual report contains a fuller description of the public benefit that the charity provides on pages 3 to 17.

## 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.

## Our committees

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

- The Audit, Finance and Fundraising Committee meets quarterly and reviews finances, risk controls, audit requirements, fundraising, and income generation activity to support and grow our work.
- The Policy Group meets quarterly and provides a steer for the charity's policy and influencing work at local, national and international level.
- The Communications and Marketing Group has been established with the aim of meeting quarterly to raise awareness and understanding of M.E., and promoting the services and support offered by Action for M.E.
- The Research Panel meets twice a year and monitors the charity's research-funded activity.
- The Remuneration and Nominations Committee meets as and when required, to make recommendations to the Board on senior appointments and related significant employment contract issues.

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

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

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

## Chief Executive

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

## Volunteers

Our brilliant volunteers add huge value to the work that we do, helping us reach and support more children, young people and adults with M.E. Some make the most of the opportunity to work with us short-term, while others have been volunteering for much longer, sometimes many years. Some work with us in our Bristol office, while others make their essential contribution from home. Many have personal experience of M.E.

Our volunteers support our work across a range of teams, services and projects including:

- sharing stories, reviews, pictures, poems and jokes for our Cheers updates – all the content comes directly from members of our Children and Young People's Community
- keeping our Children and Young People's forum a safe and fun space – all down to our young peer-moderator volunteers
- writing to children and young people severely affected by M.E., without the expectation of a reply – again, this is a service provided by some of our young volunteers
- our professional volunteer advocates, trained to empower people with M.E. to understand their rights, as part of our pilot advocacy service (see p 8)
- ensuring our support, membership and fundraising services run smoothly, and contributing experience and expertise to our communications and campaigning work
- spending time and energy to be volunteer peer mentors, offering mutual support and guidance to others affected by M.E. in Scotland through our Mentor M.E. project

- writing brilliant content for our membership magazine, *InterAction*, proofreading it to make sure everything is accurate and easy to understand, and recording articles for our Soundcloud channel.

A range of medical, research and professional advisors also give their time, energy and expertise which hugely enriches our work on a pro bono basis.

All our volunteers make a difference to the lives of people with M.E., and we could not do what we do without them. We are immeasurably grateful for the time, energy, enthusiasm and commitment they bring to helping us end the ignorance, injustice and neglect experienced by people with M.E.

### Collaborative partners

By working collaboratively with others who share our values, we can be more effective in achieving our aims and improving the lives of children, young people and adults with M.E. This includes other M.E. charities and patient organisations, health, social care and education professionals, government and senior officials, and other decision-makers.

As a member of a number of organisations and alliances, including Forward M.E. (see p 10), the International Alliance for M.E. (see p 10), Disability Rights UK, Health Conditions in Schools Alliance and the Disability Benefits Consortium, we continue to build capacity, reach more people, and achieve more by working in partnership to achieve common goals.

We also provide secretariat support to the UK CFS/M.E. Research Collaborative (see p 12), and lead the International Alliance for M.E. of patient organisations committed to influencing international decisions with the potential to affect national policy change on M.E. in the UK.

### 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 39. 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.



**I just wanted to say thank you for making the magazine more accessible by creating an audio version. What a fantastic idea! I like to browse the magazine but struggle to read more than a few lines. So, a big thank you to you and all your volunteers.**

*Sam, who listens to InterAction magazine on Soundcloud*



Our fundraising policy stresses the critical importance that no individual should use their position in Action for M.E. for personal gain, or to benefit others at the expense of the charity, our mission, or our reputation. It sets out that individuals must not act in any way that could be reasonably seen by others as compromising the independence and integrity of the charity; and that all activities must be carried out with honesty and integrity, with employees never knowingly misleading supporters. Any confidential information obtained must always be protected, and the trust of our supporters must not be violated. The policy also sets out the way in which we deal with fundraising complaints.

### Risk

The Chief Operating Officer (September 2017 to July 2018) and the Chief Executive have been responsible for the Risk Register, which is reviewed regularly by the Audit, Finance and Fundraising Committee and annually by the Board. Risks are categorised in a way that enables us to see the cumulative impact of risks and ensure that we take action to protect the quality of our work, reputation and income.

For example, by closely monitoring our income, with monthly reviews and reports to Trustees, with actions identified to minimise expenditure and increase income, we mitigate the risk that our income falls below projections. 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 2018 – 2019, Trustees were satisfied that this was undertaken in a proper manner and took a proactive role in supporting additional work in this area.

In April 2019, we contacted the Charity Commission to record a serious incident that took place in February/March. This involved gross misconduct by a senior employee, who is no longer with the charity, which could have potentially caused damage to the reputation of the charity. The Charity Commission was satisfied that Action for M.E. did what was required of us, and is taking no further action. There was no material damage to the charity.

### 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 at [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 at [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. at [www.actionforme.org.uk/volunteer](http://www.actionforme.org.uk/volunteer)
- fundraising to support our work and raise awareness of M.E. at [www.actionforme.org.uk/fundraise](http://www.actionforme.org.uk/fundraise)
- making a gift now – or consider leaving on in your will – at [www.actionforme.org.uk/donate](http://www.actionforme.org.uk/donate)



# 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 2019 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 20, 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 2 October 2019

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 2019

	Notes	Unrestricted funds (£)	Restricted funds (£)	Total 2019 (£)	Total 2018 (£)
<b>Incoming resources</b>					
Incoming resources from generated funds:					
Donations and legacies	3	599,192	224,112	823,304	1,008,781
Other trading activities	3	160,527	778	161,305	128,466
Investment income	4	1,134	–	1,134	296
Incoming resources from charitable activities	3	90,712	36,503	127,215	131,175
<b>Total incoming resources</b>		<b>851,565</b>	<b>261,393</b>	<b>1,112,958</b>	<b>1,268,718</b>
<b>Resources expended</b>					
Costs of generating funds:					
Costs of generating voluntary income	5	264,219	753	264,972	230,864
Fundraising trading: costs of goods sold and other costs		4,661	–	4,661	4,572
Charitable activities	5	718,194	289,630	1,007,824	811,361
<b>Total resources expended</b>		<b>987,074</b>	<b>290,383</b>	<b>1,277,457</b>	<b>1,046,797</b>
Net movement in funds	12	(135,509)	(28,990)	(164,499)	221,921
Reconciliation of funds					
Fund balances at 1 April 2018		499,253	233,449	732,702	510,781
<b>Fund balances at 31 March 2019</b>		<b>363,744</b>	<b>204,459</b>	<b>568,203</b>	<b>732,702</b>

All incoming resources and resources expended derive from continuing operations. The notes on p 28 to 37 form an integral part of these accounts.

# Balance sheet

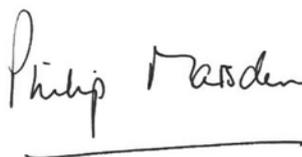
As at 31 March 2019 (company registered number 2906840)

	Notes	2019 (£)	2018 (£)
<b>Fixed assets</b>			
Tangible assets	9	25,591	2,146
<b>Current assets</b>			
Debtors	10	86,382	111,925
Cash at bank and in hand		580,160	691,592
Total current assets		666,542	803,517
Creditors: amounts falling due within one year	11	(123,930)	(72,961)
Net current assets		542,612	730,556
Total assets less current liabilities		568,203	732,702
<b>Capital and reserves</b>			
Unrestricted funds:			
General funds	12	<b>363,744</b>	<b>305,501</b>
Designated funds	12	–	<b>193,752</b>
		<b>363,744</b>	<b>499,253</b>
Restricted funds	13	<b>204,459</b>	<b>233,449</b>
Accumulated funds		<b>568,203</b>	<b>732,702</b>

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 28 to 37 form an integral part of these accounts.



Jonah Grunsell  
Chair of Board of Trustees and Directors



Philip Marsden  
Treasurer

Approved by the Board of Trustees Thursday 26 September 2019

## Action for M.E. cash flow statement for the year ended 31 March 2019

		<b>2019</b>	<b>2018</b>
Net cash flow from operating activities	See note a below	(83,311)	172,214
Net cash flow from investing activities	See note b below	(28,121)	(557)
Net decrease in cash and cash equivalents		<u>(111,432)</u>	<u>171,657</u>
Cash and cash equivalents at beginning of period		691,592	519,935
Cash and cash equivalents at end of period		<u>580,160</u>	<u>691,592</u>

## Notes to the cash flow statement

### a Cash flows from operating activities

	£	£
Net movement in funds	(164,499)	221,921
Depreciation	5,810	3,103
Financial income	(1,134)	(296)
	<u>(159,823)</u>	<u>224,728</u>
(Decrease)/increase in debtors	25,543	(79,565)
(Decrease)/increase in creditors	50,969	27,051
NET CASH FROM OPERATING ACTIVITIES	<u>(83,311)</u>	<u>172,214</u>

### b Cash flows from investing activities

	£	£
Purchase of tangible fixed assets	(29,255)	(853)
Interest received	1,134	296
NET CASH FROM INVESTING ACTIVITIES	<u>(28,121)</u>	<u>(557)</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 39. It meets the definition of a public benefit entity under FRS 102. Assets and liabilities are initially recognised at historical cost or transaction value unless otherwise stated in the relevant accounting policy note(s). The financial statements are prepared on a going concern basis. The Trustees consider that there are no material uncertainties over going concern.

The preparation of financial statements in compliance with FRS 102 Section 1A Small Entities requires the use of certain critical accounting estimates. It also requires management to exercise judgement in applying the accounting policies.

### Fund accounting

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

### Deferred Income

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

### Recognition of liabilities

Liabilities are recognised on the accruals basis.

### Incoming resources

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

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

### Resources expended

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

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

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

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

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

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

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

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

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

### Fixed assets and depreciation

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

### Pensions

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

### Taxation

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

### Operating lease agreements

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

### Financial instruments

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

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

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

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

## 3 Details of incoming resources

	Unrestricted funds (£)	Restricted funds (£)	Total 2019 (£)	Total 2018 (£)
<b>Donations and legacies</b>				
Trusts and companies	154,686	97,600	<b>252,286</b>	193,524
Donations and appeals	290,593	52,642	<b>343,235</b>	360,530
Legacies	97,039	–	<b>97,039</b>	241,545
Tax recoverable	52,874	10,167	<b>63,041</b>	52,386
Gifts in kind	4,000	–	<b>4,000</b>	4,000
Grant Income	–	63,703	<b>63,703</b>	156,796
	<b>599,192</b>	<b>224,112</b>	<b>823,304</b>	1,008,781
<b>Other trading activities</b>				
Lotteries and raffles	11,598	–	<b>11,598</b>	11,553
Christmas cards	4,045	–	<b>4,045</b>	4,229
Supplement commission	2,000	–	<b>2,000</b>	1,961
Merchandise	261	778	<b>1,039</b>	705
Events	125,496	–	<b>125,496</b>	94,050
Other	17,127	–	<b>17,127</b>	15,968
	<b>160,527</b>	<b>778</b>	<b>161,305</b>	128,466
<b>Incoming resources from charitable activities</b>				
Subscriptions	88,287	413	<b>88,700</b>	92,909
Conference fees	–	36,090	<b>36,090</b>	36,055
Charity journal	2,116	–	<b>2,116</b>	2,041
Information and publications	309	–	<b>309</b>	170
	<b>90,712</b>	<b>36,503</b>	<b>127,215</b>	131,175

Details of 2018 income	Unrestricted funds (£)	Restricted funds (£)	Total 2018 (£)
<b>Donations and legacies</b>			
Trusts and companies	126,124	67,400	193,524
Donations and appeals	308,576	51,954	360,530
Legacies	241,545	–	241,545
Tax recoverable	45,416	6,970	52,386
Gifts in kind	4,000	–	4,000
Grant Income	–	156,796	156,796
	<b>725,661</b>	<b>283,120</b>	<b>1,008,781</b>
<b>Other trading activities</b>			
Lotteries and raffles	11,553	–	11,553
Christmas cards	4,229	–	4,229
Supplement commission	1,961	–	1,961
Merchandise	377	328	705
Events	94,050	–	94,050
Other	98	15,870	15,968
	<b>112,268</b>	<b>16,198</b>	<b>128,466</b>
<b>Incoming resources from charitable activities</b>			
Subscriptions	91,647	412	92,909
Conference fees	–	36,055	36,055
Charity journal	2,041	–	2,041
Information and publications	170	–	170
	<b>93,858</b>	<b>37,317</b>	<b>131,175</b>

#### 4 Investment income

	2019 (£)	2018 (£)
Interest from cash investments in the UK	<b>1,134</b>	296
	<b>1,134</b>	<b>296</b>

## 5 Resources expended

	Unrestricted funds (£)	Restricted funds (£)	Total 2019 (£)	Total 2018 (£)
<b>Costs of generating voluntary income</b>				
Staff costs	26,627	–	<b>26,627</b>	42,939
Direct fundraising costs	108,970	753	<b>109,723</b>	77,453
Support costs – see below	128,622	–	<b>128,622</b>	110,472
	<b>264,219</b>	<b>753</b>	<b>264,972</b>	<b>230,864</b>
	Unrestricted funds (£)	Restricted funds (£)	Total 2019 (£)	Total 2018 (£)
<b>Charitable activities</b>				
Information and support services	482,113	151,708	<b>633,821</b>	533,717
Campaigning and influencing work	223,713	9,507	<b>233,220</b>	202,307
Collaborative biomedical research	12,368	128,415	<b>140,783</b>	75,337
	<b>718,194</b>	<b>289,630</b>	<b>1,007,824</b>	<b>811,361</b>

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

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

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

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

Office costs include £4,000 (£4,000 in 2018) for professional services in kind.

	<b>2019 (£)</b>	2018 (£)
<b>Governance costs</b>		
Administrative salaries – based on time spent	<b>18,986</b>	18,054
Indemnity insurance for Trustees	<b>1,603</b>	1,499
Governance training	<b>165</b>	529
Trustees' expenses	<b>2,486</b>	2,218
Meeting room hire and refreshment costs	<b>4,650</b>	441
Auditors' fees	<b>6,250</b>	6,513
Professional fees	<b>299</b>	19,699
Design and printing	<b>1,478</b>	550
Postage	<b>125</b>	–
	<b>36,042</b>	49,503

	<b>2019 (£)</b>	2018 (£)
<b>Grant activities</b>		
The University of Sussex – PHD in Biomedical Research	15,094	–
The University of Edinburgh – PHD in Biomedical Research	36,000	–
	<b>51,094</b>	–

## 6 Net movement in funds

	2019 (£)	2018 (£)
<b>This is stated after charging:</b>		
Operating lease	<b>27,062</b>	35,825
Depreciation of owned fixed assets	<b>5,810</b>	3,103
Auditor remuneration	<b>6,250</b>	6,513
Trustees' expenses	<b>2,486</b>	2,443
Pension costs	<b>18,106</b>	13,379

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 2019 was £1,866 (in 2018 it was £1,499).

## 7 Staff costs and emoluments

	2019 (£)	2018 (£)
Gross salaries	<b>558,282</b>	537,205
Employer's National Insurance	<b>50,662</b>	49,210
Pension contributions	<b>18,106</b>	13,379
	<b>627,050</b>	599,794

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

	2019	2018
Engaged on charitable activities	<b>11</b>	9
Engaged in fundraising activities	<b>5</b>	4
Engaged on management and administration	<b>3</b>	4
	<b>19</b>	<b>17</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 £82,457 (£101,338 in 2018).

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

	2019 (£)	2018 (£)
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>2,486</b>	2,443
Amounts of expenses incurred by Trustees that were donated back to the charity.	<b>737</b>	1,011
There were no related party transactions up to 31 March 2019.		

## 9 Tangible fixed assets

	Office equipment 2019 (£)
<b>Cost</b>	
At 1 April 2018	50,867
Additions for year	29,255
Disposals in year	32,621
<b>At 31 March 2019</b>	<b>47,501</b>
<b>Depreciation</b>	
At 1 April 2018	48,721
Charge for year	5,810
Disposals in year	32,621
<b>At 31 March 2019</b>	<b>21,910</b>
<b>Net book value</b>	
At 31 March 2018	2,146
<b>At 31 March 2019</b>	<b>25,591</b>

## 10 Debtors

	2019 (£)	2018 (£)
Trade debtors	<b>284</b>	352
Prepaid expenses	<b>24,066</b>	23,379
Due from HMRC	<b>1,295</b>	950
Accrued income	<b>60,737</b>	87,244
	<b>86,382</b>	111,925

## 11 Creditors: amounts falling due within one year

	2019 (£)	2018 (£)
Trade creditors	14,538	17,733
Accrued Expenses	88,684	38,448
Unpaid pension contributions	3,023	2,032
Other taxation and social security costs	17,685	14,748
	<b>123,930</b>	72,961

## 12 Funds

	General funds (£)	Designated funds (£)	Total (£)
<b>Statement of unrestricted funds</b>			
Balance at 1 April 2018	305,501	193,752	<b>499,253</b>
Transfer between funds	128,752	(128,752)	–
Surplus for year	(70,509)	(65,000)	<b>(135,509)</b>
<b>Balance at 31 March 2019</b>	<b>363,744</b>	–	<b>363,744</b>

	Tangible fixed assets (£)	Cash	Other Net current assets (£)	Total (£)
<b>Analysis of net assets between funds – current year</b>				

Unrestricted funds:				
General funds	25,591	375,701	(37,548)	<b>363,744</b>
Designated funds	–	–	–	–
	25,591	375,701	(37,548)	<b>363,744</b>
Restricted funds	–	204,459	–	<b>204,459</b>
	25,591	580,160	(37,548)	<b>568,203</b>

	Tangible fixed assets (£)	Cash	Other Net current liabilities (£)	Total (£)
<b>Analysis of net assets between funds – prior 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>

## 13 Restricted funds

	Opening balances £	Incoming resources £	Outgoing resources £	Closing Balances £
<b>Movements in restricted funds</b>				
Research	173,558	104,166	134,415	<b>143,309</b>
Scotland services	–	5,000	5,000	–
Children’s and Young People’s Service	–	36,224	36,224	–
Regional advocacy services	2,000	40,000	28,752	<b>13,248</b>
Mentor M.E.	34,148	63,703	52,742	<b>45,109</b>
Connect M.E.	15,000	–	15,000	–
Educate M.E.	8,743	–	8,743	–
M.E Friends Online	–	12,300	9,507	<b>2,793</b>
	<b>233,449</b>	<b>261,393</b>	<b>290,383</b>	<b>204,459</b>

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

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

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

**Regional advocacy** – Throughout the South West and Midlands, this project 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.

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

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

**Educate M.E.** – This project worked 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.

**M.E. Friends Online** – Our forum for adults with M.E. has more than 3,200 registered users, who share peer-support, friendship and practical tips about 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 £3,022 (£2,032 in 2018) 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.

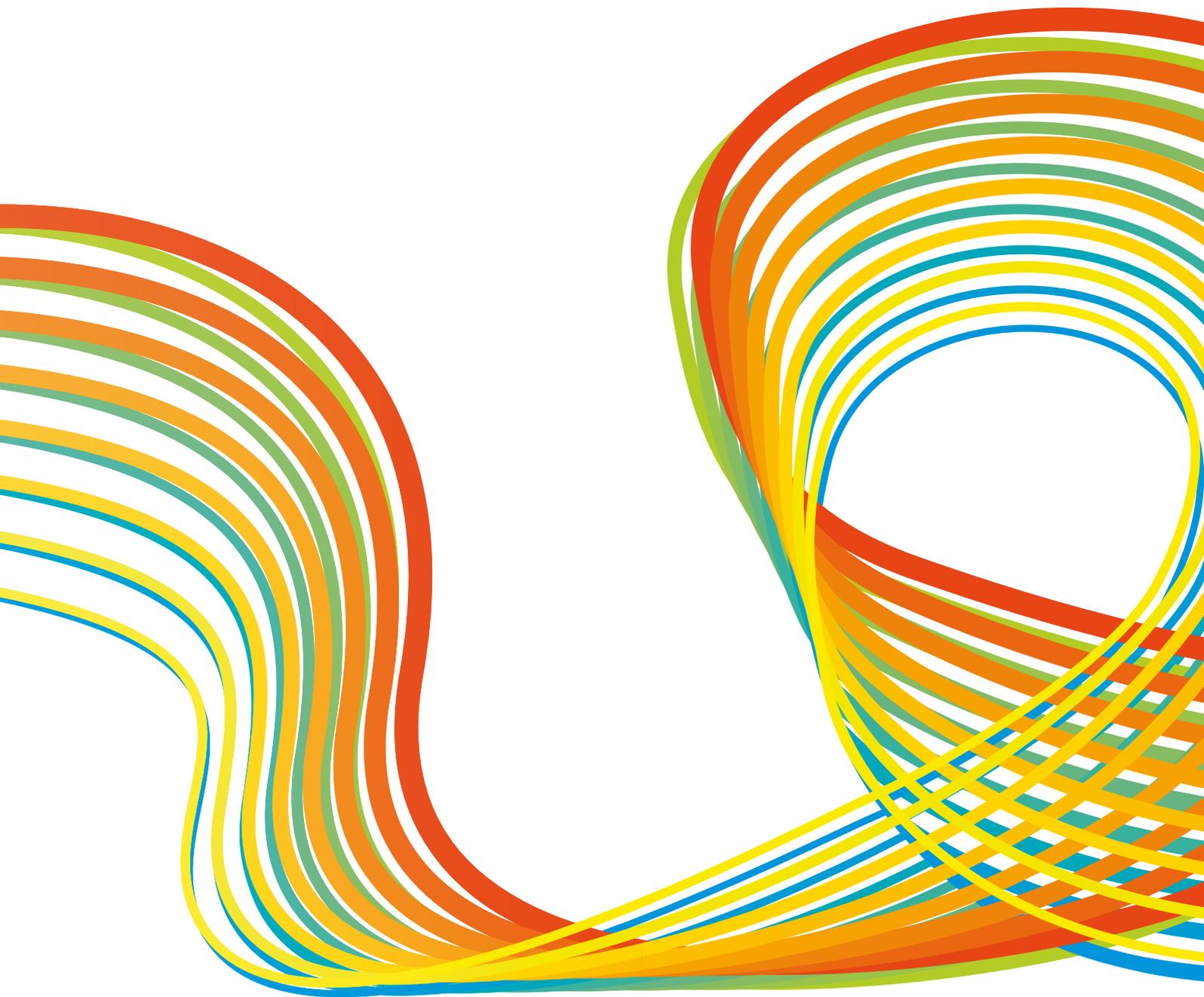
	Total Leases 2019(£)	Total Leases 2018(£)
<b>Operating lease payments falling due:</b>		
within one year	26,719	26,462
within two to five years	26,538	52,200
over five years	–	–
	<b>53,257</b>	<b>78,662</b>

## 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 at 31 March 2019.

## 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 £106,000 of which £75,333 is to be spent in the year to 31 March 2020.



## Legal and administrative details

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

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

### Bankers

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

### Auditor

Moore Stephens  
30 Gay Street, Bath BA1 2PA

## Trustees and Directors 2018 – 2019

### President

Clare Francis MBE

### Founding President

Sue Finlay

### Vice President

Martin Arber

### Patrons

Lord Bragg  
Julie Christie  
Lord Puttnam CBE  
Alan Cook CBE

### Board of Trustees

Jonah Grunsell, Chair  
Philip Marsden, Treasurer  
Colin Batten  
Gordon Berry  
Christopher Cundy  
Alison Deeth (from Jul 2018)  
Andy Dougan  
Sue Hardy  
Phil Murray (from Oct 2018)  
Jane Stacey  
Ed Stephens  
Matt Symonds  
Katherine Thomas (to Nov 2018)  
Jane Young

### Chief Executive

Sonya Chowdhury

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Dr Gregor Purdie  
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“Thank you so much. In the ten years I have suffered with my health, this is the best information I have been given. I will look into all of this and hopefully be able to get back on track.”

Information and Support Service user



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