

Action for M.E. CEO update March 2020

WELCOME to the quarterly CEO update which provides a brief snapshot of the work and successes that **you** have helped to create.

Big Give - a successful third year!

We had yet another successful year taking part in the Big Give Christmas Challenge, raising nearly £145,000. We exceeded our target by 30% and received 398 donations to our online campaign – 76 of these were from people who had never given a gift before. The Big Give Christmas Challenge is such an important campaign for us, bringing in roughly 12% of our income each year. Thank you to all those who took part.

Our services

Funds from the Big Give help us to provide services to support children, young people and adults with M.E. and reduce the isolation they experience. In a recent survey of people calling our Information and Welfare Support Service:

- 100% said they feel better supported after using the service
- 97% feel listened to
- 81% increased their understanding of their rights and options
- 81% increased their knowledge of other services they could access
- 42% feel better able to manage their illness
- 100% said they would recommend the service to someone in a similar position.

One respondent said, "I do not know what I would have done without the support and advice. Staff are friendly and very knowledgeable and make you feel listened to. I would highly recommend this service."

Celebrating our first Honorary Patron

We are delighted to welcome Ondine Upton in this new, voluntary role this month recognising her valuable contribution to the charity over many years. Ondine will work with us to help raise the profile of the charity and the illness and income to support our critical work.

Research Collaborative conference

The annual two day conference, run by Action for M.E., was held on 10-11 March in Bristol. While most of the international speakers were unable to attend due to Coronavirus, a full programme was delivered with some presentations given remotely.

Films can be viewed on our Action for M.E. YouTube channel at www.tinyurl.com/CMRC2020films

Priority Setting Partnership (PSP)

We have been awarded around £100,000 from three Government-backed research funders to deliver a PSP. The aim is to identify and prioritise the top ten questions that people with M.E., carers and clinicians agree are the most important, that have not been answered by research to date, using a methodology tried and tested with a range of other illnesses and health issues, through the James Lind Alliance.

We are now recruiting a steering group of people with M.E., carers and clinicians to oversee this work. You can read more on the PSP website at www.psp-me.co.uk

Coronavirus

All our support services to children, adults and their families with M.E. will continue despite the evolving situation with Coronavirus. This is our top priority. At a time when demand for our services is increasing, we have already seen a decline in income; we are working hard to minimise impact.

Colleagues are all working remotely and flexibly, as we have closed the office, to ensure we meet the needs of people with M.E. We are updating our website regularly with the latest advice at www.actionforme.org.uk/coronavirus

"For the first time, I feel that someone understands my condition." Service user

Thank you once again for all your continued support.

