



NEIL RILEY

Recently, we announced the full details of our decision to invest nearly £200,000 in ME research. The grants were awarded to:

- The ME Biobank to continue with their vital work until such time as the resource becomes self-sustaining,

- Dr Karl Morten and his team at Oxford University who will be investigating the recently reported blood plasma anomalies,

- Dr Keith Geraghty at Manchester who will obtain and report on patient evidence in that crucial period before and just after diagnosis. They represent our continuing commitment to quality research. You can read the full press statement on our website with comments from Dr Charles Shepherd and the three grant recipients.

We are a small medical charity and I feel very proud of all our achievements. Management and strategic direction is provided by a dedicated team of trustees, including several, like Dr Shepherd, who work on a daily basis, volunteering their time for free.

Our small team of experienced staff are committed to supporting the needs of this community. We have a full-time member and more part-time staff who work from home often on a flexible basis. We also have a terrific team of volunteers up and down the country who help ensure your telephone helpline is available 365 days a year.

Almost everyone who works for the ME Association has personal experience of M.E., is currently living with the condition or has a loved one who has been affected. This knowledge and understanding is what helps us to be who we are – delivering a quality service when and where it's needed.

We provide much-needed support, reliable information, a voice when it's needed, and we believe research investment is a key priority. We couldn't do any of this without your help and we are incredibly grateful for your trust.

Thank you

Neil Riley, *Chairman of Trustees*

The ME Association...

We're working for YOU!

With the approach of Christmas, a difficult time of year for many of our members, we would like to acknowledge those of you who have, once again, helped keep the ME Association show on the road.

The surprising thing about this charity is that we've come to this point at all. For beneath the trappings that we often tell you about, our survival year after year depends on a host of heroes who go about their work, largely unseen but certainly not unappreciated.

We load heaps of resource into supporting the work of our volunteers on the ME Connect helpline. There are dozens of them who are all led by and supported by a professional manager. They are rostered to answer the phones at home so we can keep the shifts running every day throughout the year, including throughout the coming Christmas holiday. Yes, even on Christmas Day itself and New Year's Day, we expect the lines to be buzzing.

If you're feeling lonely and fed up, if you haven't had a real conversation with anyone for days, or you just want to find out something to do with this illness or this charity, you know where to find us.

You thought paying for research in our field was easy? Simple – we put out appeals, you help the money roll in, we sign the cheques



to this research group or that interested academic who's starved of funds... Job done!

You couldn't be more wrong!

For beneath the jingle all the way statements – like our latest Ramsay Research Fund announcement of almost £200,000 funding to researchers in Oxford, Manchester and London – a huge amount of work has to be done by Dr Charles Shepherd and his team. And that work is done largely out of sight.

First, we need to suss out where the research we're interested in is taking place and whether any reputable scientist there wants to do it. Then we need to tease out accurately costed and intellectually rigorous applications. Our trustees at some stage have to weigh up the merits of these against our own financial priorities in the Ramsay Research Fund. Even approval of individual applications doesn't mean the process always stops there.

If a particular line of inquiry is so complex that even our research team doesn't fully understand all of it, then – before we can finally greenlight it – the application has to go out for peer-review by a scientist who knows the subject inside out. As the years have gone by, we have kept in touch with a range of senior scientists who can offer this kind of guidance.

The £200,000 announcement was the easy part. It can often take a year or more for a research application to be worked up before it is put to trustees for final confirmation.

Because it's your money that we're spending, we have to be particularly careful that it is spent wisely.

BIOBANK

The UK ME/CFS Biobank, which the MEA has nurtured from its very beginnings, has become a first port of call for researchers from round the world.

The ME Association has provided funding to cover all running costs of the ME Biobank since 2008. This has amounted to c.£380,000 and we have just agreed to provide an additional £100,000 over the next two years until such time as this vital project becomes self-sustaining. We are the only organisation that has supported this vital resource throughout this period. Dr Shepherd now chairs the Biobank Steering Committee.

The biobank – run by the Cure-ME team at the London School of Hygiene and Tropical Medicine (LSHTM) – has now shipped out blood product samples to university research groups in 10 countries overseas. Inquiries keep coming in.

This busy programme means that highly qualified people can turbocharge research into the causes and biological basis of this horrid illness without having to wait months, even years, to recruit severely sick patients into their study programmes. In the biobank, the team continue to match ME/CFS blood samples with blood taken from patients with multiple sclerosis and with healthy controls. And the work at LSHTM is enabling the small team of bright scientists there to publish their own high-quality studies in top-notch scientific journals.





This is vital to maintaining a lively scientific community.

The actual physical product – blood samples and the products derived from them – is actually housed within a much larger biobank elsewhere in central London, at a facility run by University College London and the Royal Free Hospital. This saves a huge amount of money.

Dr Luis Nacul and Dr Eliana Lacerda are in charge of the ME Biobank and lead the research that has resulted from it. They are supported by Caroline Kingdon and a dedicated team who, among other things, visit patients at home to collect blood and clinical data. Dr Nacul splits his time between London and his new role as medical director of the chronic complex diseases programme at the British Columbia Women's Hospital in Vancouver.

Read more about the biobank here:
cureme.lshtm.ac.uk

Biobank photographs by Yasmin Crawford:
yascrawford.com



Where would we be without the late Dr Melvin Ramsay?



Dr Melvin Ramsay studied the illness in the huge Royal Free Hospital outbreak in 1955 and went on to help found the ME Association, when it was run by a couple of ladies in a Victorian villa at Stanford-le-Hope, Essex. His descriptions and definition of the

illness are still often hailed as the best ever of classic ME.

Dr Ramsay went on to become the charity's first president, often contributing to early editions of our magazine.

He wrote powerfully against the renaming of the illness as chronic fatigue syndrome and said he lived to regret ever having let the psychiatrists, McEvedy and Beard, have sight of his notes about the Royal Free outbreak. That pair went on to write a paper which denounced the outbreak as an example of mass hysteria.

Melvin's daughter, the actress Louie Ramsay, later become one of our patrons and so did her husband – British tough guy actor George Baker.

Tribute to Melvin Ramsay's memory has now been paid in America, where one of the ME/CFS charities has also named their research fund after him.



ABOUT THE ME ASSOCIATION

Recent grants were made from the ME Association Ramsay Research Fund, named in honour of Dr Melvin Ramsay who helped establish the charity and became its president.

We have around 5,000 paid-up members who receive our superb ME Association magazine **ME Essential**. We receive funds and support from members and an increasing number of non-members.

Our website, www.meassociation.org.uk, attracts around 1.1 million unique page views each year and we believe it is one of the most popular resources in the world. The **What is ME?** section and the **MEA Blog** are hugely popular. We will shortly be launching a new and easier to navigate website.

We are followed by around 21,000 on Facebook, 15,000 on Twitter and 2,300 on our newly launched Instagram page. The number of people viewing or engaging increases dramatically during specific events e.g. **Severe ME Week** and **ME Awareness Week**, or when key news breaks. We reach upwards of 10,000 people every day on Facebook alone, and recently reached 252,000 people with a single post!

We don't employ an expensive CEO. Instead we have a terrific team of trustees who provide strategy and management on a voluntary basis, including our Chairman, Neil Riley, and our

medical adviser and trustee, Dr Charles Shepherd. Trustees also attend and report on the important external conferences and meetings that take place. Dr Shepherd has been working incredibly hard with the NICE guideline committee in the hope that the 2020 clinical guideline will be more reflective of the patient experience. Trustees are supported by a full-time member and part-time members of staff at head office and other part-time staff who work flexible hours from home. We also have a large number of dedicated volunteers who help ensure **ME Connect** - our telephone helpline - is available 365 days a year for people needing to talk or seek help. We have recently recruited two social media experts - both of whom have M.E.

All of the people working for the ME Association have personal experience of M.E., have loved ones affected by the disease or have been working for the charity for a long time and have a deep understanding of the condition and the issues that continue to surround it.

Our main priorities are to provide support, reliable information, a voice and representation, and funding for vital medical research.

We are eternally grateful to all our supporters who enable us to help make the UK a better place for people with ME.

ME SUPPORT

Most of our resource goes into providing support. We do this by answering cries for help and providing extensive information, by answering phone-calls at head office, emails or messages via social media or via ME Connect and the helpline. We also convey information and generate discussion and debate of key issues. We gather information in the form of surveys that can then be used to try and improve things e.g. with NICE and the influential clinical guideline on ME/CFS. And, of course, we spend a lot of time working on new research grants.

We publish over 90 leaflets, mostly written by Dr Shepherd, which are a cornerstone of what we produce and available at small cost (or free) from the website shop and by ordering through ME Essential. The very popular 'Purple Book' (clinical and research guide) is available in print and also on Kindle. We also send this to hundreds of medical professionals each and every year for free.

