

# WHAT WE DO AND WHY

## FROM THE CHAIRMAN

**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 Charles Shepherd, who work on a daily basis, volunteering their time for free.**

In December 2019, we announced the full details of our decision to invest an additional £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



*Dr Charles Shepherd  
Trustee and Hon. Medical Adviser*

and report on patient evidence in that crucial period before and just after diagnosis.

You can read the [full press statement](#) on our website with comment from Dr Shepherd and the three grant recipients. We regard research investment as vitally important and have made grants totalling well in excess of £1million.

- On 12th May 2020 we will be announcing a pilot study that will use an adapted form of cardio-pulmonary exercise testing to help record physiological changes during daily activity in people with M.E. This study will be carried out by researchers from Leicestershire and Oxford Universities and will be led by Dr Nicola Clague-Baker who is also a member of Physios 4 M.E. It will monitor people in their own homes using a variety of measures and is the first study of its kind certainly in the UK.

Our 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.



*Neil Riley  
Chairman of Trustees*

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 good quality research investment to be 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*

## WHAT WE DO AND WHY WE DO IT

M.E. (myalgic encephalopathy or encephalomyelitis) is a complex multisystem disease with a wide range of disabling symptoms. The ME Association is here to support people through all stages of their illness because we desperately want to see everyone get the help they need and, through research, help to develop an effective treatment and one day even a cure.

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 Chairman, Neil Riley, Medical Adviser, Dr Charles Shepherd and trustee Ewan Dale, who all contribute daily.

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 on a contractual basis from home.

We also have a large number of dedicated volunteers who help ensure ME Connect – [the telephone helpline](#) – is available 365 days a year for people needing to talk or seek help. We recently recruited two social media experts – to help us deal more effectively with the rapid growth in activity on Facebook, Twitter, and Instagram.

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.

## LOBBYING FOR POSITIVE CHANGE

Trustees attend and report on the important external conferences and meetings that take place. Dr Shepherd has been working incredibly hard recently with the NICE guideline committee in the hope that the new and highly influential [clinical guideline on ME/CFS](#) will be more reflective of the patient experience when it is finally published in early 2021.

We are active members of Forward ME (see below for more information) which is an influential advocacy group comprising charity and political representatives and is led by the Countess of Mar and Carol Monaghan, MP. We are also

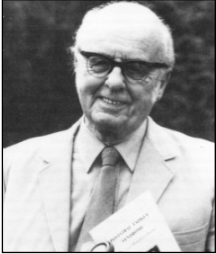
on the board of the [CFS/ME Research Collaborative](#) (CMRC) which is made up of scientists, clinicians and advocates.

A major application from scientists, clinicians and patient representatives who are members of the CMRC for potentially the largest ever genetics study, was submitted to the Medical Research Council and National Institute of Health in January 2020. It has involved extensive consultation with these funding bodies, and it will require 20,000 DNA samples from people with the condition. It could provide vital new information about disease causation. For more information and to

register your interest, please visit the [ME/CFS Biomedical Partnership](#) website.

We work alongside Dr Nina Muirhead on medical education initiatives as part of the CMRC Medical Education Group, and we continue to work closely with Carol Monaghan MP who has led several successful debates about M.E. in parliament. Ms. Monaghan has re-established an [All-Party Parliamentary Group \(APPG\) on M.E.](#) which began meetings in January 2020. The MEA provides secretariat support to the APPG and we are represented by Dr Charles Shepherd.

## THE RAMSAY RESEARCH FUND



We named our [research programme](#) in honour of Dr Melvin Ramsay (pictured left) who helped

bring awareness of M.E. to the medical establishment.

He also helped establish the ME Association and was its president for a number of years. Dr Ramsay remained closely involved with the charity until his death in 1990.

You can read more about Dr Ramsay's work and how he viewed the disease in his book,

which is available to order from the [website shop](#).

We spend a lot of time working with scientists on new research grants because funding good quality biomedical research is a key priority for this charity. Recent grants totalling £200,000 were made from the ME Association Ramsay Research Fund.

The [M.E. Biobank](#), which the ME Association has nurtured from its very beginnings, has become a first port of call for researchers from round the world. The Biobank was launched in August 2011 following extensive consultation with professionals

and patient representatives. To date the Ramsay Research Fund has invested c.£380,000 in the M.E. Biobank which will cover running costs until 2021 when we hope the project will be self-sustaining.



## ADVOCACY

### FORWARD-ME

Forward ME was established by the Countess of Mar (pictured right) and recently marked its ten-year anniversary. We have worked with Lady Mar on a wide range of issues ranging from child protection and medical education through to NHS services and the ever-present need for biomedical research.

Forward ME played a vital role in lobbying for a full review of the NICE clinical guideline. Dr Shepherd is currently working very hard as a member of the guideline committee to help ensure that the new guideline will better reflect the actual patient experience. Publication has been delayed due to the

coronavirus pandemic, but is expected early in 2021.

Regular meetings of Forward ME see Lady Mar invite a range of professionals from the health, social care and research fields, as well as ministers, politicians and civil servants from the various government departments that have an effect on M.E. policy, to the House of Lords.

This provides important opportunities for us to raise the profile of M.E. and put forward our case for improved medical education, better NHS services and more biomedical research.

Lady Mar announced her retirement from the House of Lords on 1st May, but she will continue as Chair of Forward



ME. We gave thanks to her [stalwart advocacy efforts](#) over the years and The Telegraph featured an article about her distinguished parliamentary career. Carol Monaghan, MP for Glasgow North-West, will also continue as Deputy Chair. Ms. Monaghan has led several successful debates in the House of Commons and is also Chair of the All-Party Parliamentary Group (APPG) on M.E.



## SUPPORT WHEN IT'S NEEDED

We put a lot of resource into giving as much support to people affected by this disease as we can. We do this by answering cries for help and providing extensive information, through phone calls at head office, emails or messages via social media or ME Connect.

### ME CONNECT

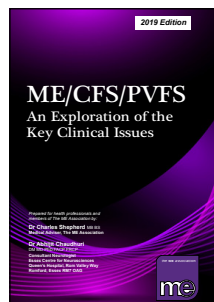
**ME Connect – the telephone helpline** is available 365 days a year with a team of volunteers under the excellent professional supervision of Hilary Briars. **Call 0344 576 5326 during the hours of 10am-12noon, 2pm-4pm and 7pm-9pm.**

We also convey information and generate discussion and debate of key issues. We gather information in the form of surveys and petitions that can then be used to try and improve things e.g. with NICE, or with debates in parliament, or medical education initiatives.



We publish over **90 leaflets**, mostly written by Dr Shepherd, MEA Trustee and Honorary Medical Adviser, which are a cornerstone of what we produce and available at small cost (or free) from the website shop and through ME Essential

– our exclusive and top-quality magazine for members.



The very popular 'Purple Book' ([The clinical and research guide](#)) is available in hard-copy and also on [Kindle](#)

and is updated annually. We also send this authoritative publication to hundreds of medical professionals each and every year for free.



We have around 5,000 paid-up members who receive ME Essential. We receive funds and support from members and an increasing number of non-members. Support for the ME Association continues to grow, most often by non-traditional methods e.g. social media.

### MEMBER COMMENTS

"If it wasn't for the ME Association I don't think I would have been able to move from being very severely ill to where I am today."

"I like and trust that many people working for the ME Association have first-hand knowledge and experience of M.E."

"The ME Association has been there since I first became ill and given support when all else has failed. Its continuing presence is very important to me."

Visit our [Membership](#) page to read more comments and join the ME Association today!

■ [M.E. Factsheet: What you need to know about M.E.](#)

■ [M.E. Research Summary: Explains the research developments](#)

■ [The Ramsay Research Fund: Details the investments we have made into vital biomedical research](#)



## WEBSITE AND SOCIAL MEDIA

Our website 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 be launching a new and easier to navigate website very soon, so stay tuned!

We are followed by around 21,000 people on Facebook, 15,000 on Twitter and 2,300 on

our newly launched Instagram page. The number of people viewing or engaging with our posts increases dramatically during specific events e.g. Severe ME Week and ME Awareness Week, or when important news breaks.

We reach upwards of 20,000 people every week on Facebook alone, and have been known to reach 252,000 people with a single post!

We are eternally grateful to all our supporters who enable us to help make the UK a better place for everyone affected by M.E.



## THE UK ME BIOBANK

The M.E. Biobank, which the ME Association has nurtured from its very beginnings, has become a first port of call for researchers from round the world.

The Biobank was launched in August 2011 following extensive consultation with professionals and patient representatives. To date the Ramsay Research Fund has invested c.£380,000 in the M.E. Biobank which will cover running costs until 2021 when we hope the project will be self-sustaining.

We are the only organisation that has supported this essential resource throughout this period, and 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,

and inquiries from researchers 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 M.E. blood samples with blood taken from patients with multiple sclerosis and with healthy controls. And the work at LSHTM is enabling this small team of dedicated scientists to publish their own high-quality studies in top-notch scientific journals.

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 M.E. Biobank by visiting the [Research section](#).

■ You can also visit the [M.E. Biobank's](#) own website.

■ Biobank photographs by [Yasmin Crawford](#).



## THE CMRC

The ME Association is Member of the Board of the CMRC of the CFS/ME Research Collaborative (CMRC) and works alongside Prof. Stephen Holgate, Prof. Chris Ponting and other renowned scientists, charity partners and other patient representatives to help advance biomedical research into M.E.

An [important new project](#) that could see a £3.5million genetics study funded by the MRC and NIHR that would involve 20,000 people with M.E. resulted from discussions at the CMRC. We are awaiting a funding decision from the Medical Research Council.

We are also closely involved with the CMRC Medical Education Group which is led by Dr Nina Muirhead. This team is completing work on a new CPD course for medical professionals that will help them understand more about M.E., how to reach a correct diagnosis and advise on the best management options. Other initiatives are also continuing, including panel discussions with local professionals up and down the country and representative at key medical conferences. The new CPD course will hopefully be announced in May 2020.

### MEMBER COMMENTS

"The ME Association makes me feel less isolated. I believe that ME is real and physical, and I like that the ME Association is wholeheartedly behind research to prove this."

## THE REAL ME



M.E. (myalgic encephalopathy or encephalomyelitis) is a complex multisystem disease with a wide range of disabling symptoms. The ME Association is here to support people through all stages of their illness.

■ M.E. is hard to accept. We help people understand and come to terms with M.E.

■ M.E. can be difficult to diagnose. We help people get the diagnosis and medical help they need by providing accurate information and working to improve medical understanding and education.

■ M.E. wrecks lives. We help people struggling to cope practically, emotionally and financially. We also work to shield them from remedies that offer false hope.



■ M.E. is often invisible. We help people explain their illness to disbelieving relatives, colleagues, friends and health professionals.

■ M.E. is misunderstood. We regard research investment as a key priority and work hard to put as much investment into good quality biomedical research as we can in the hope that we will ultimately come to know what causes M.E. and how it can best be treated.

■ M.E. silences. We campaign and speak out for those who can't defend themselves.

The ultimate goal of the ME Association is to find a cure for people with M.E. If we continue to work together we will discover biomarkers for the disease that lead to effective treatments and a cure!

M.E. can affect anyone at any time of life. It is more common and more functionally debilitating than better-known diseases like Multiple Sclerosis. The Real M.E. Campaign put real faces to M.E. and helped challenge misconceptions.

If you would like us to include your images and story on our website, social media and work with you to publish an article in the news-media, then do please get in touch: [feedback@meassociation.org.uk](mailto:feedback@meassociation.org.uk)

If you would like to submit a story for publication in our magazine ME Essential, please email the editor: [caroline.cavey@meassociation.org.uk](mailto:caroline.cavey@meassociation.org.uk)



## THE ME ASSOCIATION

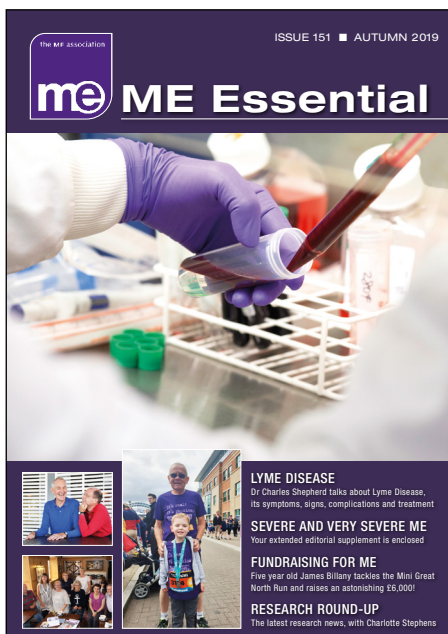
### PLEASE SUPPORT OUR VITAL WORK

We are a national charity working hard to make the UK a better place for people whose lives have been devastated by an often-misunderstood neurological disease.

If you would like to support our efforts and ensure we are able to inform, support, advocate and invest in biomedical research, then please donate today.

Just click the image opposite or visit our [JustGiving page](#) for one-off donations or to establish a regular payment. You can even establish your own fundraising event.

Or why not join the ME Association [as a member](#) and be part of our growing community? For a monthly (or annual) subscription you will also receive [ME Essential](#) – quite simply the best M.E. magazine!



### The ME Association:

- Provides information on M.E. and campaigns on issues such as research, the NICE guideline, NHS service provision and care
- Provides support through our ME Connect helpline, ME Essential members magazine and our website and social media
- Funds biomedical research – including the UK ME/CFS Biobank which is managed by an expert team at the London School of Hygiene and Tropical Medicine – through the Ramsay Research Fund
- Is a member of the Forward ME Group of charities and patient representatives that is chaired by the Countess of Mar, and the CFS/ME Research Collaborative, chaired by Professor Stephen Holgate, which aims to raise the profile of M.E. and attract greater research investment

#### Further information:

[M.E. Research Summary](#)

[Ramsay Research Fund Factsheet](#)

**ME Association:** [ME/CFS/PVFS An Exploration of the Key Clinical Issues](#)

**ME Association:** [An Index of Published ME/CFS Research](#)

**ME Association:** [Website](#)

**ME Association:** [Facebook](#) and [Twitter](#) and [Instagram](#)

### The ME Association website shop:

You can download leaflets and buy gifts from our [website shop](#) or by downloading and completing our [Order Form](#). If you are a member of the ME Association, you will receive an order form with your quarterly magazine.

The following literature is available to download or order:

#### Medical Management

Leaflets about the medical management of ME/CFS – 51 topics covered.

#### ME Connect

Useful leaflets based on the concerns expressed by people who

have used our ME Connect helpline.

#### Diet & Nutrition

Our dietary advisers provide key information to help you maintain a healthy diet even when ill.

#### General Information

Guides to going to university and travel insurance – with other great leaflets.

#### Fundraising Leaflets

You'll be welcome to download our free fundraising leaflets.

#### Benefits & Social Care

Includes guides to Universal Credit and PIP and obtaining Social Care.

#### 'To Whom It May Concern' letters

For when you need to explain to others how M.E. can affect your ability to do things.



# The Ramsay Research Fund

*the research arm of the ME Association*

***Please help us to further The Ramsay Fund's invaluable work in supporting biomedical research into M.E. (Myalgic Encephalopathy)/Chronic Fatigue Syndrome.***

***The Ramsay Research Fund was set up to find answers to:***

- how and why M.E. starts.
- how we can develop a test. And better still...
- how we can cure more of the 250,000 people with M.E. in the UK today.

***With your help, that day could be much sooner.***

## **You can donate**

■ By cheque (payable to The ME Association) and with a covering note explaining that you wish your donation to go to research

■ Online through our JustGiving campaign page for Ramsay Research Fund: [www.justgiving.com/campaigns/charity/meassociation/ramsayresearchfund](http://www.justgiving.com/campaigns/charity/meassociation/ramsayresearchfund)

■ Or if you would like to make a regular donation, please contact our office to set up a standing order or use this link and type RRF in the message [www.justgiving.com/meassociation/Donate](http://www.justgiving.com/meassociation/Donate)



**ME Association's Ramsay Research Fund**  
**Striving to find ways to help those living with M.E. today.**

The ME Association,  
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