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The ME Association Chairman's Statement for 2024

January 9, 2025

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It has been a full and exciting year at the ME Association. The demand for our services has increased and there are more and more people joining our charity and coming to us for help. We have recruited additional staff to help cope with this surge in order to provide a bigger and better service to all who ask.

I would like to thank our members and all our supporters who have donated their time and their money to ensuring that our charity is able to meet its objectives which are:

- to offer relief to persons of all ages with Myalgic Encephalopathy (ME)/Chronic Fatigue Syndrome (CFS) through the provision of information.
- to further educate in all aspects of the illness.



- to support research into the illness including the making of grants and to publish the useful results of that research.

Information

Our website is a knowledge tree of information about the illness and is continually updated with the latest news about ME/CFS and Long Covid.

With our quarterly ME Essential Magazine, our weekly newsletter, our website and our social media channels, we inform, educate and campaign for all people with ME/CFS.

ME Essential is our major regular contact with our members and continues to deliver news, opinion, answers to readers' questions and engage readership through life stories and advice.

The reach and impact of our social media team has increased rapidly over the last year. On Facebook, Instagram and X, we continue to inform and encourage dialogue throughout the ME Community and elsewhere. For the latest news and comments on ME/CFS, people come to us. We are constantly looking at new ways in which to connect with people with ME/CFS and those who influence how you, the patient, are treated and understood.

We have expanded our Communications Team with the appointment of two new members of staff to manage our digital platforms. We have over 70k social media followers reaching over 3.5m people and a million website users. We intend to expand our activity across other platforms; use more video content; become even more accessible; and make more platform specific content to reach more people.

ME Connect

ME Connect is our charity's way of delivering support and information in a personal way. Our staff and volunteers are professionally managed and highly trained.

The service was re-launched this year with the appointment of Katharine Leat in January. Phone, emails, and social media messaging all now fall under the same management. We identified there was scope for development and in the summer of 2024, the trustees approved a 12-month pilot scheme:

- Increased opening hours.
- Employed staff working alongside existing and new volunteers.



- Freephone number.
- Reduced response time for email responses.
- Change of phone services provider to improve efficiency and reduce running costs.

Now:

- Four part-time staff have been appointed.
- Eight new volunteers have joined the well-established team.
- September 2024 the pilot scheme was launched.
- October 2024 (first full month of pilot) recorded 300 calls answered, the highest number in a month to date. An increase of nearly 50% from the previous record.
- A new training programme is being delivered for new staff and volunteers.
- A new phone line service provider 'Call Handling' will begin in February 2025, specialist provider to many charities.
- Improved reliability and reduced costs to The MEA.
- Additional safeguarding measures.
- Calls received through a VCC removing the long-standing requirement for landline phones.
- Research has been undertaken into the most appropriate platform for an online community forum.
- A new group of volunteers to begin training January 2025.
- Ongoing skills development training programme throughout 2025.
- An online community forum will be launched in 2025.

Research

Your charity is committed to finding a diagnosis and a cure for ME/CFS. It's why we are funding or considering funding just about every research group here in the UK that is carrying out biomedical research into the cause or management of ME – a total of 12 different centres or individuals.

- The [MEA's Ramsay Research Fund](#) (RRF) is currently funding in 2024, and are considering funding in 2025, research costing well over £500,000. We pay all the basic running costs of the [ME Biobank](#), which is part of the UCL Biobank, at the Royal Free Hospital in London. The ME Biobank supplies blood samples and



anonymised clinical data from people with ME/CFS to research groups in the UK and abroad.

- We are also funding post-mortem research in collaboration with the [Manchester Brain Bank](#).
- Money is going into research into mitochondrial dysfunction and metabolomics at the University of Oxford, including a new PhD position in 2025.
- Money is funding Physios for ME, including a pilot study on lactate levels in people with ME/CFS – University of Liverpool.
- Under consideration is research into the underlying physiological cause of post exertional malaise.
- There are two separate studies into diagnostic biomarkers at the University of Surrey and the University of Oxford.
- We are funding the management of dysautonomia – orthostatic intolerance and POTS study at the [University of Leeds](#); a study into ME/CFS in pregnancy at the University of Newcastle and a clinical trial of a drug treatment, where the protocol has been agreed and contractual arrangements are in progress

As you can see from the above, we are using substantial research funds to achieve the aim that we all seek, a diagnosis and cure for ME/CFS.

Fundraising

Research, information and support for people with ME/CFS can only be provided with resources, money and people. Fundraising plays a huge part in enabling the charity to do this work. With our newly formed fundraising team, led by Jim Morrison, an experienced professional in the charity world, we aim to attract funding for large-scale research trials to build on the work we are already doing.

Governance

We are committed to undertaking a comprehensive review of our current Articles. That review will look at the Code, the Charity Commission's Model Articles and any other source of good practice. To this end we shall consult widely and transparently including recruiting an independent charity governance professional to advise the charity. We have the same aspiration of all our members, namely, to ensure that the ME Association is run to the



best standards and continues in its charitable mission.

Capital reserves

The ME Association has substantial capital reserves. This has been obtained, firstly, by the generosity and commitment of our members and supporters. Secondly, the commitment of our staff and trustees over the last 20 years. Thirdly, through the prudence of the board of trustees over that time.

However, the purpose of a charity is to use its money for the furtherance of its aims and not to leave it in a bank account. The trustees are well aware of this and some time ago we set out a 5-year strategy to use that capital reserve to further the charity's objectives. To this end we looked at new projects that would benefit the lives of people with ME/CFS. We spoke about these at the recent AGM.

As the chosen projects come on stream, they will need financing, and we will use our reserves to do that. That will result in a substantial reduction of the reserves to the level that is appropriate for our charity and which level is guided by the Charity Commission's recommendations on reserves. It sounds easy to spend money and it is. But to spend money wisely and bring about an improvement to the ME Community is hard. Potential projects need detailed planning and project management. Pilot schemes must be tried, staff recruited. To make this happen we have established a special projects team, led by a full-time Special Projects Manager, and they are reviewing a selection of projects which require substantial funding. A feasibility study relating to the benefit and cost effectiveness of these projects is underway.

One study that is underway covers health and social care. We have launched a project whose aim is to engage with healthcare clinicians and decision-makers to implement the NICE Guideline in their services. We started this by talking to the Integrated Care Board (ICB) of Buckinghamshire, Oxfordshire, and West Berkshire. This ICB is now working on a review of existing ME/CFS and LC specialist services with a view to providing integrated services in each of the 3 counties. We are also engaging with 5 other ICBs in England and the 7 Health Boards in Wales that are developing similar services.

At the end of October 2025, we will assess what we have achieved and look at how the project could be extended into other areas of the country, by expanding the healthcare team, and providing a bridge between patients and healthcare services. This would



essentially embed healthcare into the ME Association and will require significant

additional funding for at least a further 5 years. That's why we need the capital reserves that we hold so that projects like this can be funded and bring real benefit to us all.

The Annual General Meeting

Our AGM was held in December, and it was a delight to see such interest in the ME Association from all who attended in the video conference meeting. Members came forward with some excellent suggestions as to the future direction of the charity and we will be actioning a number of these.

Looking to the future

Feedback from the ME Community is that, as a charity, we need to communicate better about what we do. To this end we are developing a year-round communications programme informing you, our members, about where money is spent and how it will benefit everyone with ME/CFS.

The ME Association is now a bigger, better organisation and we have been changing with the times as we've grown. We now have Team Leaders who are responsible for everyday operational control. The teams are vibrant, full of new ideas. Times are changing. You only have to look at our Social Media output and our ME Connect services to see this. There has, over the years, been a steady turnover with new trustees taking the place of those that have left. All trustees have to be elected by the members, and it is their decision whether to elect or re-elect.

Our charity's rules allow for up to 8 trustees and we only have 6 at the moment. We are open to applications to supplement the tremendous capability and experience we have across legal, information technology, marketing and communications, medical, scientific and business. We need people with experience of life, the willingness and ability to work each day with our teams, professional skills that you've acquired. And, above all, your passion to improve the lives of people with ME. We are sure you will enjoy the role.

Finally, I would like to thank our dedicated, hardworking staff, volunteers and trustees for their commitment to help those with this illness. They work so hard for all of us and do it with a passion that clearly demonstrates what the word "Charity" means. This bringing together people who care about a cause so they can make a difference is what the ME Association is all about.

