Chairman's Statement 2026

The ME Association

As we approach the end of 2026, I am pleased to reflect on another important year for the ME Association. It has been a year of considerable progress, significant investment in research, continued development of our services and important changes to the way the charity is governed and managed.

It has not been without its challenges, particularly in an increasingly difficult financial environment. Nevertheless, our commitment to improving the lives of people affected by ME/CFS remains as strong as ever.

Research and Scientific Progress

Research remains one of our highest priorities, and our commitment to biomedical research continues to be substantial.

Through the Ramsay Research Fund, we have made significant financial commitments to research projects, including our £1.2 million investment in the Rosetta Stone project at Imperial College London. Our overall research commitments now exceed £2 million, reflecting our determination to improve scientific understanding of ME/CFS and ultimately help identify effective treatments.

We have also welcomed the Government's £4.7 million commitment to the Sequence ME research programme, an encouraging recognition of the importance of biomedical research into this devastating illness.

For those living with ME/CFS, scientific progress can understandably seem painfully slow. We must continue to encourage greater investment and collaboration, whilst ensuring that the funds generously entrusted to us are used effectively.

Supporting Our Community

Providing reliable information, practical assistance and compassionate support remains central to everything we do.

Our ME Connect service continues to provide a vital source of help and reassurance to people affected by ME/CFS, their families and carers. Through our Freephone support line, email and online services, our dedicated staff and volunteers provide support to those who often face considerable isolation and uncertainty.

Our Health and Social Care team has continued to develop its work, providing valuable information, guidance and advocacy. During the year, the Trustees agreed to establish this service on a permanent footing, recognising the contribution it makes to the ME/CFS community.

Our publications, website and communications activities also continue to provide trusted and accessible information, reaching an audience far beyond our membership.

As demand increases, we must continually assess how best to use our resources, balancing our ambitions with the need to ensure that our services remain sustainable.

Raising Awareness and Influencing Change

The ME Association continues to play an important role in raising awareness of ME/CFS and influencing healthcare policy, research and service provision.

Through our involvement with Forward-ME, engagement with parliamentarians and participation in national discussions, we continue to advocate for better understanding, improved healthcare and greater recognition of the needs of people living with ME/CFS.

Particular attention must be given to those who are severely and very severely affected, many of whom remain largely invisible to society and face enormous difficulties accessing appropriate care and support.

Although progress is now being made, there remains a considerable gap between what people with ME/CFS need and the services available to them. We will continue to challenge that situation.

Governance and Organisational Development

Much of 2026 has been devoted to implementing the recommendations of the independent Governance Review commissioned in 2025.

The Review identified 49 recommendations covering governance, organisational structure, leadership and strategic planning. Considerable progress has been made, with the majority now completed or actively progressing.

An important development has been the introduction of a new management structure. These changes were designed to strengthen accountability, improve management and allow Trustees to concentrate more fully on their strategic responsibilities.

We recognised that changes of this nature would take time to become established and committed to reviewing the arrangements after 12 months. That review is now underway, providing an opportunity to assess what has worked well and where further improvements may be necessary.

Good governance is not simply about structures and policies. It is about ensuring that the charity operates effectively, transparently and in the best interests of those it exists to serve.

Strengthening the Board

I am particularly pleased that during 2026 we have welcomed one, and potentially two, new colleagues as Associate Trustees, with the possibility of a third joining us in the near future.

This is a positive development, bringing fresh perspectives, additional experience and new ideas to the Board. Our Associate Trustee arrangements provide an opportunity for prospective Trustees to become familiar with the charity before progressing towards full trusteeship.

We have also continued to examine Trustee tenure and succession planning as part of the Governance Review. Legal advice is now being sought on appropriate amendments to our Articles of Association, with proposals expected to be presented to members at an Extraordinary General Meeting in March 2027.

Financial Sustainability

The financial challenges facing charities across the UK have continued throughout 2026, and the ME Association is no exception.

Our substantial research commitments and the development of our services have placed increasing demands upon our resources. Historically, generous legacies have enabled us to build reserves and make significant investments, but legacy income is unpredictable and recent levels have not matched those of previous years.

Although traditional fundraising income has shown encouraging improvement, we must recognise that our current level of expenditure cannot continue indefinitely without corresponding growth in income.

The Trustees are therefore taking a careful and responsible approach to financial planning, controlling expenditure whilst protecting essential services and ensuring the long-term sustainability of the charity.

The generosity of our members, supporters and donors remains fundamental to everything we achieve. Whether through membership, fundraising, donations or gifts left in wills, every contribution makes a real difference.

Looking Ahead

As I reflect on the past year, I am proud of how much we have achieved, but equally conscious of the challenges ahead.

Some of the decisions we have taken have not been easy, and there will undoubtedly be more difficult decisions to make. However, I firmly believe that we are moving in the right direction and building a stronger organisation for the future.

Being Chairman of the ME Association is both a privilege and a responsibility that I take very seriously. I would like to thank my fellow Trustees for their support, advice and willingness to tackle difficult issues, and our staff and volunteers for their dedication, compassion and professionalism. Much of their work takes place quietly, behind the scenes, but it makes a real difference to people's lives.

I am equally grateful to our members, supporters, fundraisers and donors, whose continued generosity and belief in the ME Association make our work possible.

Above all, my thoughts are with those living with ME/CFS, particularly those who are severely and very severely affected, and the families and carers who support them.

It is easy, when dealing with the day-to-day responsibilities of running a charity, to become absorbed in meetings, finances, policies and decisions. But behind everything we do are real people whose lives have been profoundly affected by this illness. We must never lose sight of that.

I am immensely proud of all that the ME Association has achieved during 2026, and sincerely grateful to everyone who has helped make it possible. It has been a year of real progress, shared commitment and achievements. There is so much to be positive about, and yet even more to look forward to. As we approach a new year, I do so with renewed enthusiasm, optimism and confidence that, together, we can continue to make a real and lasting difference to the lives of people affected by ME.



David Allen

Chairman of the ME Association