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Chairman's Statement for 2025

December 15, 2025

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Includes:

- [Strengthening Our Voice and Advocacy](#)
- [Expanding Research and Scientific Understanding](#)
- [Support for Patients, Families, and Carers](#)
- [Building Community and Awareness](#)
- [Operational Resilience and Governance](#)
- [Looking Ahead](#)
- [Trustee Recruitment](#)
- [Acknowledgements](#)



It is my privilege to present the Chairman's Statement for 2025, a year marked by meaningful progress, ongoing challenges, and renewed determination in our mission to improve the lives of people with Myalgic Encephalomyelitis (ME), including those living with post-infectious conditions and Long COVID that overlap with ME/CFS.

Strengthening Our Voice and Advocacy

Throughout the year, the ME Association has continued to stand firmly with people whose voices are often unheard. We intensified efforts to ensure that policymakers, healthcare leaders, and research institutions understand the urgent need for better services, compassionate care pathways, and increased biomedical funding.

Our submissions to government consultations, participation in advisory groups, and public-facing campaigns have helped place ME firmly on the national health agenda. Although systemic change remains gradual, our influence continues to build.

Expanding Research and Scientific Understanding

2024–25 saw significant strides in [biomedical research](#), supported by the continued generosity of our members and donors. We expanded grants to studies exploring immune dysfunction, post-infectious triggers, autonomic impairment, and potential biomarkers, while pursuing collaborations with clinicians and scientists nationally and internationally. These efforts contribute to a growing global network determined to unravel the complex biology of ME.

This year, we are committing nearly £2 million to research, including [£1.1 million for the Rosetta Stone study](#), the largest single investment in biomedical research ever made by a UK charity in this field. This groundbreaking work aims to help world-leading scientists uncover shared pathways between ME/CFS and Long COVID.

Support for Patients, Families, and Carers

Supporting our community remains the heart of our work. Demand for our services continued to grow, particularly among individuals with severe or very severe ME and those newly affected following viral/triggering illnesses.



Our [helpline](#), information services, and online resources remain a lifeline for thousands, offering trusted guidance, emotional support, and practical help at every stage of illness. This year, we also launched [new educational materials](#) focusing on pacing, symptom management, and navigating disability and workplace rights, along with the launch of a dedicated panel for those severely affected.

Building Community and Awareness

Raising awareness and public understanding is essential to improving quality of life for people with ME. In 2024–25, we expanded our digital outreach, engaged new audiences through community events and public campaigns, and strengthened partnerships with employers and healthcare organisations.

ME Awareness Month featured our most visible campaign yet, amplifying patient stories and highlighting the profound impact of this illness.

In September, we hosted our [Lives We Cannot Live exhibition](#) at London's Oxo Gallery, in partnership with filmmaker and photographer Jeremy Jeffs. It was a truly special experience, generating over £150,000 in free publicity, reaching new audiences; and we were delighted to meet so many people, members and non-members alike, those living with ME/CFS, as well as visitors curious to learn more.

Operational Resilience and Governance

Behind the scenes, the Association has continued to prioritise governance, financial sustainability, and operational efficiency.

The charity's financial position remains positive. However, with increasing demands from additional staffing and the awarding of significant research grants, we are operating sustainably on our current reserves while preparing for a restructuring of our management framework. A formal review of the organisational structure, including roles such as CEO or COO, will be undertaken when financially and strategically viable. Over the next 12 months, we will place a strong emphasis on income generation to support our work and secure long-term sustainability.

Following the last AGM, and at members' request, we commissioned an [independent governance review of the charity](#). The review produced 49 recommendations, ranging from minor procedural updates to substantial long-term structural changes. To date, 14



recommendations have been completed, with a further 22 in progress, including a new proposal for the management structure. The remaining recommendations involve longer-term actions, which will be addressed in due course.

We have also invested in new digital infrastructure, improved reporting and transparency, and strengthened volunteer engagement. These initiatives enable us to better serve our members and position the organisation for long-term stability and growth.

Looking Ahead

The coming year presents both challenges and opportunities. Our priorities for 2025–26 include:

- Pushing for equitable healthcare,
- Accelerating biomedical research,
- Maintaining support services, and
- Ensuring that every person with ME feels seen, believed, and valued.

With our major commitment to research, the next 12 months will emphasise consolidation, allowing income streams to stabilise and providing space for necessary restructuring. We will continue to keep members informed on the progress of the governance review and the resulting recommendations.

Trustee Recruitment

We are seeking new Trustees to strengthen our Board. The charity's rules allow for up to eight trustees, and with five currently in post, and we are currently looking at two potential new trustees, we welcome applications from individuals who bring real-life experience, professional skills, and a willingness to work collaboratively. Above all, we are looking for people who share our passion for improving the lives of those living with ME, or who care for someone with ME.



This role offers a meaningful and rewarding opportunity to make a tangible difference in the lives of people affected by this condition.

Acknowledgements

Finally, I extend my heartfelt thanks to our dedicated staff, volunteers, and trustees for their unwavering commitment. Without their efforts, none of this would be possible. Bringing together people who care deeply about a cause, and empowering them to make a lasting difference, lies at the heart of the ME Association.

We are deeply grateful to our members, donors, partners, and the wider ME community. Your strength and perseverance inspire everything we do. Together, we will continue to work toward a future where ME is fully understood and where meaningful treatments, compassionate care, and recognition are realities rather than aspirations.

David Allen,

Trustee and Chairman of The ME Association



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