Macular Society
Beating Macular Disease

Macular Society

Draft minutes of the Annual General Meeting 2025

Date: 20 January 2026
Time: 18:00h–19:15h
Venue: Zoom (online)

Present:

Cecilia Bufton (CB)	Chair of Trustees (Chair of the meeting)
Louise Perry	Honorary Treasurer (LP)

In attendance:

Ed Holloway	Chief Executive Officer (EH)
Ruth Bamford	Director of Finance and Governance (RB)
Jess Kirby	Director of Services (JK)
Emma Malcolm	Director of Income & Transformation (EM)
Amina Akhtaru	Executive Assistant to CEO (AA)

Plus, approximately 130 members, with some variation in attendance numbers during the meeting.

1.Quorum
There being a quorum present, the meeting proceeded to business.

2. Welcome and introductions
The Chair welcomed everyone to the meeting and introduced herself, explaining the format and structure of the meeting:

It was explained that several Trustees and members of the Senior Leadership team were in attendance at the meeting, and they would be introduced as they either presented or answered questions from members.

The Chair explained that papers for the meeting were available on our website, and members would also have received them in their winter issue of Sideview in December.

The Chair explained that one of the items on the agenda was that the meeting would be taken through the Society's annual report and accounts and there would be opportunity to address members' questions, including questions which were submitted in advance.

The Chair explained that the meeting would be recorded to enable the Society to produce accurate minutes.

The Chair explained that, in relation to any agenda items which included a member vote, those joining on a PC, laptop, Mac or tablet, would see a pop-up box appear with the item number and three possible options to vote – for, against and abstain.

Members were asked to click the option they wished to vote for, then click submit. The Chair explained that sufficient time for members to do this would be provided.

The Chair went on to explain that for members joining via teleconference, they would be transferred to a separate meeting room where they could give their votes verbally.

The Chair reminded those present that only voting members [and their proxies] could vote and that all the votes would be validated to ensure they were just from members or their proxy.

The Chair explained that for those participating as a proxy, they would have notified their name and email address previously. When counting votes, the number of proxy votes held would be included.

In total 136 members had registered to attend.

53 members had assigned proxy votes, to a total of 14 people.

Those individuals hold between 1 and 14 proxy votes, and have been reminded individually how many proxy votes they hold.

The Chair explained that after the voting concluded, a few minutes would be spent counting these proxy votes as well as those cast by telephone.

After a summary of activities during the year had been given, there would be an opportunity to ask questions.

The Chair confirmed that the Society had received a number of questions in advance, and the meeting would do its best to answer these as well as questions raised during the meeting. However, the meeting needed to finish by 7:15pm to allow the My Macular and Me webinar to take place.

As described in the governance guidelines, it was the Chair's role to manage how questions and issues for discussion were handled. This included collating and distilling issues into common themes, and taking into account the available discussion time during the meeting.

The Chair noted that if members would like to ask a question during the meeting they could do so by using the chat function. They could also raise their hand using the 'React' function in Zoom to indicate that they wished to ask a question.

3. Agenda item 1 - Minutes of the AGM held on 10 December 2024

The Chair noted that the first agenda item was to receive the minutes of the previous annual general meeting.

The Chair noted an error in the version of the minutes circulated with Sideview.

Within this version, we incorrectly stated that Cathy Yelf resigned 11 July 2024 and was also appointed 1 July 2024.

This should have read: Cathy Yelf, Chief Executive and Company Secretary (resigned 11 July 2024).

The Chair apologised for this error.

The Chair noted that there was no requirement under either company law or the articles for the minutes of the AGM to be approved by members, so there was no vote on this item. However, the meeting was paused for any questions or points of correction specifically on the minutes of the previous meeting.

No questions were raised.

4. Agenda item 2 - Annual Report and Accounts (Year Ended 31 March 2025)

The Chair noted that the next agenda item was to receive the annual report and accounts.

The Chair noted that, again, there was no requirement either under company law or the articles for members to approve the annual report and accounts, but that the trustees wished to take the opportunity to summarise the Society's work from 1 April 2024 to 31 March 2025.

The Chair introduced Ed Holloway, the CEO, to give a summary of our work last year. The CEO summarised the main work:

4.1. Beating Macular Disease with the best advice and support

During the year our Helpline recorded nearly 13,000 significant support actions on topics covering all macular conditions, treatments and low vision aids. Every one of these contacts represented vital support or information being provided to people living with macular disease.

We also provided practical and emotional support to almost 350 people through our befriending service, and our counsellors provided care to over 500 people.

At 31 March 2025, 325 peer support groups were operating, a slight decrease compared to the previous year, and significantly below the pre-pandemic level. Of these groups, 283 met face-to-face, 11 groups combined face-to-face with virtual meetings, and 31 groups met virtually.

We are extremely grateful to the 1,023 people who volunteer for us, giving their time and support to the Macular Society and people affected by macular disease. However, in common with many charities, recruiting volunteers continues to be extremely challenging, impacting on our peer support network.

We continued to hold our monthly My Macular and Me webinar sessions, enabling people living with macular disease to hear the latest research and news directly from researchers and clinicians. The webinars attracted 2,077 people at the live events and more than 36,000 views of the recordings.

The annual conference was again delivered online and more than 5,500 people registered. Another 4,000 had watched the recording by the end of March 2025. Registrants came from across the world and the Society continued to reach significantly more people than it could at a physical event.

4.2. Beating Macular Disease by finding a cure.
2024-25 was an exciting time in macular research. A short overview was given of the five research priorities and the key activity in the year:

In patient focused research we had our research accepted for publication in the journal Eye Open. The piece looked at where AI is acceptable in macular treatment decisions and the results would be shared in Sideview

In our academic grants, the Society championed early career researchers and supported collaboration with researchers in the fields of aging and mathematical modelling to bring more skills into macular research. The Society awarded its first postdoctoral fellowship with the Daphne Jackson Trust (DJT) and had also partnered with the Medical Research Council to deliver more fellows in coming years.

Accelerated clinical trials – the Society was progressing through the design of an enhanced clinical trial approach for research and drug trials. This aimed to speed up the setup and recruitment to trials and provide better national access to trials, so treatments could make it to patients as quickly as possible.

In translation, the Society noted its excitement when academic research funded by the Society, progressed to therapeutic or commercial development. This was an area that would receive greater focus in the coming years.

Technology and innovation – The Society worked closely with technology developers across the sector, and took a particular interest in the development of new approaches to detecting and monitoring disease, as well as solutions to improve quality of life. There was notable ongoing work with multiple technology developers to ensure their work was co-designed with patients and Macular Society Members. The Society was particularly interested in solutions which meant people could assess their vision from home, so that time at a hospital or clinic could be spent focused on engaging with clinicians about their condition, rather than lengthy visits with batteries of tests and assessments.

In the period ending 31 March 2025, we funded £868k in research grants.

This included:

- 2 project grants totalling £484k
- 1 fellowship totalling £141k

- 1 PhD studentships totalling £120k
- 5 seedcorn grants totalling £119k
- 2 travel grants totalling £4k

The research team actively engaged with local groups to present research updates and the latest news on treatments. In this period the team presented at 28 meetings around the country.

4.3. Making Vision Matter - Beating Macular Disease by improving eye health

Our primary activity in this area is a partnership called The Eyes Have It. This is a partnership of the Macular Society, Fight for Sight, Royal National Institute of Blind People, Association of Optometrists, Royal College of Ophthalmologists and Roche Pharmaceuticals Ltd (‘Roche’). Roche has funded the activities of the partnership.

Working collaboratively across the eye care sector, we advocate for and champion improvements to patient care and outcomes. Our ambition is for everyone to have access to the right care, where and when they need it.

The key aim of TEHI was to secure political support for a national eye health strategy for England. Ophthalmology is the biggest outpatient specialty in the NHS with more than 8 million appointments a year. The cost of treating macular diseases such as wet AMD and diabetic macular oedema represent some of the highest hospital prescribing costs of all disease areas. The structure of our eye care service is no longer fit for purpose and requires systemic reform to be able to cope with the eye health needs of an ageing population. We believe that cannot be achieved effectively without a national plan in place.

Building on the success of TEHI report, ‘Laying the foundations for the future of eye health in England’ the group has focused on engaging with new ministers and members of parliament following the general election and change in government. The partnership hosted Westminster Eye Health Day in November 2024 and has responded to the 10-year health plan for England with eye health specific recommendations.

The Society is also part of the Vision Partnership of eight eye charities that are seeking to identify ways for the sector to work together more effectively. In 2024/25 work concentrated on:

- Creating a ‘patient support pathway’ to complement the NHS eye care pathway, highlighting the key points at which patients require information, advice and support from diagnosis and throughout their life with a sight-threatening condition or a visual impairment.
- Promoting the needs and abilities of visually impaired people in the workplace. As part of this work, we partnered with the Thomas Pocklington Trust to employ three visually impaired interns.
- Creating an online ‘tech selector tool’ to help visually impaired people navigate to the best technology tool.
- Creating an online research data hub to be a repository for the sector’s key research reports.

During 2024/25 we continued to engage with the NHS in the redevelopment of eye care services at more local levels and in the devolved nations.

The CEO introduced Louise Perry (LP), the Macular Society’s Honorary Treasurer, to give an overview of our financial performance during the year.

4.4. Financial overview

The Honorary Treasurer then proceeded to summarise the key aspects of the financial reports and accounts.

The report and financial statements presented to this AGM are for the twelve-month period to 31 March 2025. The comparative figures are for the fifteen-month period 1 January 2023 to 31 March 2024.

Our total income for the year was £8.9million with total spend of £7.6million giving an overall surplus of £1.2million before investment revaluations.

The charity's surplus for the year reflects the impact of some temporary reductions in expenditure in response to the previous period's deficit. Both the fundraising and research budgets were temporarily cut, neither of which would be sustainable in the long term.

In addition, there were some significant timing issues in relation to both income and expenditure. As an example, a large legacy cleared probate earlier than expected increasing income for the year.

Whilst the in-year surplus was positive, the Society did not expect this to be a longer-term shift in the balance between income and expenditure.

The charity finished the year in a strong financial position with cash and cash equivalents of £6.8million with £3.9million held as unrestricted reserves. This is ahead of our target free reserves level of £2million purely due to the timing differences at the financial year end referred to earlier.

The Report and Financial Statements to 31 March 2025 were the first to be audited by our new auditors Sayer Vincent LLP. The previous auditors had been in place for many years, so Sayer Vincent enabled a fresh approach with greater scrutiny of certain aspects of the organisation. As well as the clean audit report they have provided Trustees with a detailed management letter identifying ways where improvements can be made. Some of these recommendations have already been made and further improvements are expected in the next twelve months.

The financial performance of the organisation continues to be closely monitored by the Trustees.

4.5. Regional transformation
The CEO then highlighted the work affecting the Society's regional team and local groups.

This is the AGM for the 2024-2025 financial year, so our focus is on the organisation's work between 1st April 2024 and 31st March 2025.

However, time was spent discussing more recent events, as it was known that some members had been concerned by things they had heard.

At the start of the current financial year, a consultation process was begun regarding proposed changes to the regional team. Like many charities and organisations of all kinds, from time to time it is necessary to look at the structure to ensure sustainability and effectiveness.

There were two main reasons for these proposals:

Firstly, whilst in the financial year just reported a financial surplus had been achieved, as noted earlier this reflected the impact of some temporary reductions in expenditure in response to the previous period's deficit, as well as some timing issues in relation to both income and expenditure.

We do not believe it reflects a longer-term shift in the balance between income and expenditure.

Indeed, in the previous year (2023-2024) the Society had a deficit between income and expenditure of almost £1.2m, and had budgeted for a significant deficit in the current (2025-2026) financial year. To ensure financial sustainability, there needed to be a balance across charitable expenditure so it supported all the Society's work, as well as investing to grow income.

Secondly, whilst it was known that volunteers valued their relationships with their regional managers, many things had not worked well in the previous structure. It was believed there was a need to create new roles focusing on issues like volunteer communications, recruitment, and group finances, all elements which had been under-resourced in the previous structure.

In response to this need for change, an extensive consultation process was led. This focused on staff who could be affected by the proposals, but also involved discussions with many volunteers, and feedback was received from across the community.

Final decisions had been made on the structure of the new community networks team, and existing staff had been appointed to new roles. Recruitment was underway for the small number of roles where there were vacancies, and many strong applications were being received for these roles. The Society had also said goodbye to some staff who it was unable to appoint to new roles. The Society thanked those staff for their commitment to the organisation and wished them all the very best for the future.

In December, calls were held with volunteers to explain the new structure and how decisions had been shaped by feedback from staff and volunteers, and information about the new team was also available on the website. The Society confirmed its commitment to monitoring carefully how well the new structure worked, and implementing changes or improvements where needed. Recent calls with volunteers, senior staff and Trustees had been greatly valued, and these would be booked in regularly during 2026 and beyond.

Contrary to some of the comments heard, the Society remained completely committed to continuing a network of local groups and having in place a staff structure that gave them the support they needed. The new community networks team was a significant team. Indeed, it remained the largest single team in the organisation.

Any change of this nature can be challenging, but as some members were aware, this process had been particularly difficult.

In particular, a podcast had been established which had spread misinformation and untruths about recent months at the Macular Society. The Society expressed deep disappointment at the misinformation being spread by this podcast and sadness at the approach that some former colleagues were taking.

Some of the individuals involved had also initiated legal proceedings against the organisation. The Society was confident that the organisation had acted appropriately throughout, and legal costs were being incurred to respond to these claims and protect the organisation. These costs were being carefully managed and monitored, and an appropriate provision would be made in the budget for the upcoming financial year.

Trustees had been kept fully informed and involved as appropriate, and regulators such as the Charity Commission had also been kept properly informed.

Due to the sensitivity of these issues, and the existence of ongoing legal disputes, the Society was not able to go into further detail.

Throughout all of this, the goal had always been, and remained, to make the biggest difference to the lives of people living with macular disease. This was what guided the decisions of the senior leadership team and the Trustees.

The Society exists to beat macular disease and would continue to run a professional and effective organisation with zero tolerance for bullying and harassment, funding world-leading research, and providing life-changing services for those who need them.

This had been a particularly challenging time for the organisation, and for staff at all levels and in all areas of the charity. However, income levels had been seen in line with expectations, and the Society's wonderful supporters continued to give valued donations to support its work. Research and services work was also progressing well, and the Society remained ambitious about its plans to beat macular disease.

The Society expressed confidence that it would emerge from this period a stronger, better and more professional organisation which would make an even bigger difference in the fight against macular disease.

4.5. Questions submitted in advance on annual report and accounts

The CEO then handed back to the Chair, who took the meeting through the questions that had been received on the annual report and accounts in advance of the meeting, noting that questions on other matters would be taken at the end of the meeting

The Chair read out the questions:

Several members have asked why the annual report referred to a plan to maintain only 220 local groups, which was significantly fewer than the Society had.

Another member also asked how many local groups the Society has in the UK.

The CEO answered and apologised for any concern caused by this number. He said that this target was set early in 2025 and was always intended to be an absolute minimum number, with the expectation that we would continue to have significantly more groups than this. The CEO apologised and acknowledged that this should have been presented differently in the annual report. He reassured the members that the Society currently had around 300 groups, and as the new team became established, it was hoped that community networks would grow and develop. The CEO noted that the precise number of currently active groups would be known once the annual return process was completed at the end of the financial year.

A member asked what cost savings had been achieved by the restructuring of the Regional Management Team and what the current financial position was.

JK, Director of Services responded and said as we didn't appoint people to all of these roles within the new structure yet, we didn't have a final figure.

Our initial proposals were intended to save approximately £450,000 per year, but we made some changes following the consultation process, which included increasing capacity in some areas. We suspect the final figure will probably be savings of approximately £400,000 per year.

A member asked what had happened to the regional managers who looked after the groups.

The CEO replied and said as he had mentioned earlier, at the end of last year, we completed a restructure of our regional team. Whilst the new community networks team does have few staff, many of the previous regional managers have roles in that new structure. Others are no longer with the organisation.

Another member asked two questions on the annual report and accounts:

On page 70, local group income is stated as £84,000. On page 92 expenditure on local group activities is stated as £178,000 (up from £94,000 in the 2024 15-month period).

Why has expenditure increased and how is it funded, as it is more than double the local group income?

RB, Director of Finance and Governance addressed this question and said the information we receive from individual groups varies considerably and for 2024/2025 we did not receive as much detail we would have liked in group returns.

Our new auditors, Sayer Vincent LLP, took a different approach to auditing group balances than our previous auditors. All the ringfenced funds could be verified because the receipts and payments are managed centrally.

For those groups with bank accounts, we agreed a fresh approach with the auditors, only carrying forward the closing position of groups where the amount could be verified against bank statements.

This meant that any balances that could not be verified to actual bank statements were written off against group expenditure. This resulted in expenditure being higher for 2024/25 in our accounts.

The same member also asked:

On page 83 there is a list of restricted income for practical and emotional support services for people affected by sight loss in Scotland, Northern Ireland and Wales. Is there an appropriate amount from unrestricted income ringfenced for practical and emotional support services for people affected by sight loss in England? If so, how much?

RB addressed this and said for the coming year, a new approach was outlined which would engage with Group Treasurers and work with them to gain as much information as possible. A new role for Groups Finance, sitting within the finance team, would be appointed to. The sole purpose of this role would be to work with and support the groups with their financial management.

Regarding restricted income for services within devolved nations, this was typically from funders such as the Big Lottery who had a range of different funding programmes in different parts of the UK. The level of funding able to be secured from these programmes would vary from year to year and would mean there would often be differences in the Society's work in different nations. The aim was to significantly grow restricted income across the UK to enable the provision of additional services, alongside funding other work.

A member raised a concern that a lot of money seems to be spent on fundraising, how does this compare to other similarly sized charities and are the Board confident it represents good value for money?

The Honorary Treasurer responded and said that we regularly compare our spend on fundraising with other charities and our figures are comparable in proportion to the income raised.

The same member also said The Annual Report indicates the importance of income from legacies to the Charity, but many members have already / or are talking about changing their wills to exclude the Macular Society as a result of the recent changes the charity has made, which they are unhappy about. What is being done to rebuild their confidence?

The Honorary Treasurer explained that all income came from fundraising, and if money was not spent on fundraising, income would not be raised, which meant the Society could not fund more services and spend more on research.

Regarding legacies, nothing had been seen in the data at that point to indicate that individuals had chosen to change their wills. New pledger numbers for that year were also higher than ever seen, so people were engaging and letting the Society know of their intention.

Regarding the approach taken – the Society was engaging with all of those individuals who had indicated they had included or were intending to include a gift in their Will to the Macular Society, thanking them for the decision they had made and reaffirming the positive impact that legacies had on enabling the Society to continue its work towards beating macular disease. This was done through stories of others who had pledged and the gifts received.

Another member said that the organisation has been much criticised over the last 9 months, and how much has this cost in lost revenue?

The CEO responded and said that whilst the Society was aware of some criticism of its decisions, it was important to put this into the context of a large charity doing wonderful work every day to support people living with macular disease and to find a cure.

Fortunately, the Society's incredible supporters continued to value the work being done, and so far that year, income had been matching the budget very closely.

As always, the Society was so grateful to everyone who chose to support its work, including of course the members.

The Chair noted that a member had asked a number of questions on our financial position, including why cuts were necessary in the current financial year and whether our financial position was disclosed to auditors.

Another member had also asked questions about our financial position and the need to make savings.

RB responded and said that like any organisation the Society needed to continuously monitor its financial position, and from time-to-time changes to its structure might be needed to ensure financial sustainability.

RB noted that, as the CEO mentioned earlier, the changes to our regional team were in part about ensuring a balance between income and expenditure, but also about working in the most effective way possible.

There was not a panic to reduce costs, and whilst the reductions were significant, at around 6% of our annual expenditure we would not describe them as problematic.

Our auditors were fully informed of our financial position, and it is accurately described in our annual report and accounts.

5. Agenda item 3 - Receive notification of appointment or reappointment of officers and members of the Trustee Board

The Chair reported that no new Trustees were appointed during the period.

Sheena George and Sobha Sivaprasad both retired on 31 March 2025 when their term of office came to an end.

A recruitment process was currently underway for new Trustees, and it was anticipated that new appointments would be made soon.

6. Agenda item 4 – to approve the appointment of Auditors and authorise the Directors to fix their remuneration

The Chair noted that, last year, members approved the appointment of Sayer Vincent as our new external auditors. The Society had worked with our previous auditors for many years, and during 2024 our Audit and Risk Committee led a tender process to select new auditors.

Trustees had been pleased with Sayer Vincent's work and felt that they had provided a good level of challenge and scrutiny, and that they would continue to do so.

Trustees recommend the re-appointment of Sayer Vincent as our auditors, and the authorisation of Directors to fix their remuneration.

A member asked a question on opportunities for members to review their scope of engagement before appointment, to ensure that they produce a sufficiently broad analysis of the society's activities in relation to public and charity sector regulation?

(Before voting on the resolution) CB asked RB, Director of Finance and Governance, to answer the question.

RB said Sayer Vincent are one of the leading auditors for charities of our size. The scope of the engagement is fully compliant with auditing standards. They were selected following a full tender process in 2024 and this would be their second year completing the audit.

Under our governance guidelines, Trustees are responsible for the overall leadership and governance of the organisation, which includes considering the performance of auditors and considering their terms of engagement. This work is led by our Audit and Risk Committee, which includes Trustees with extensive experience in this area.

Before the meeting proceeded to a vote on the proposed resolution to re-appoint Sayer Vincent as auditors, the Chair reminded members how to vote, with those who had joined via a computer, tablet or smartphone having the ability to vote via a pop-up notification on Zoom. Members who had dialled in via a telephone were placed in a separate room to give their votes verbally.

Where attendees had been assigned proxy votes, and the Society had been properly notified of these, these proxy votes would be included in the vote count.

Due to the complexity of voting via phone and proxy votes, there was a short pause whilst the votes were tabulated.

The meeting proceeded to vote on the resolution to appoint Sayer Vincent as our auditors and to authorise Directors to fix their remuneration.

The Chair noted that votes of those attending via phone and additional proxy votes would be recorded and noted that it would take a few minutes to count the votes (whilst the votes were counted, the meeting proceeded to agenda item 5).

Two members who had joined from the same computer were reassured that, as members, both their votes would be counted, including the proxy vote.

Similarly, another member who was having difficulties casting his vote electronically was reassured that he could submit his vote via the chat or verbally. He confirmed verbally that he was voting against the appointment of the auditors.

A member raised a point of order in relation to voting accessibility for telephone participants. He raised concern that telephone participants were unable to unmute and cast votes during the voting process, resulting in some members being unable to vote. It was an unsatisfactory experience for him.

The Chair and JK acknowledged the concern and confirmed that attempts would be made to capture votes from those unable to vote by telephone.

Before finalising the results of the votes, the CEO said the Society would be contacting anyone who was unable to vote via the telephone to make sure their vote was recorded.

Once all votes had been cast, including phone votes, the CEO provided a summary of the results of the votes:

In total, 123 votes had been cast (81individuals voting with additional proxy votes counted on top)

- 32 votes for the motion = 24%
- 69 votes against = 54%
- 26 abstentions = 21%

Therefore, the resolution to re-appoint Sayer Vincent as auditors was not passed. Members had not voted to reappoint the auditors.

The CEO noted that as an organisation there was a statutory requirement to have auditors, and therefore the Society would need to reflect on how to move forward to ensure it remained compliant with company law and had an effective audit in place.

7. Agenda item 5 – any other business including questions submitted in advance

As noted earlier, the meeting would do its best to answer as many questions as possible, and to help with this, similar questions would be grouped together.

Three members asked why local groups were being reduced or abolished and one member (via the chat) asked about building up support for groups. Four members also asked about support for groups.

The CEO responded and said as had been explained in the earlier presentation, the Society had no plans to reduce or abolish local groups. Instead, the aim was to secure them into the future by supporting them in a coherent and sustainable way.

The new structure enabled the Society to focus on historically under-resourced areas like recruitment of volunteers, which was essential to keep the peer support offer lively. Regional presence would continue via the Community Engagement Managers, who would be looking at the overall peer support picture across an area and maintaining engagements with health professionals and devolved governments.

The volunteer and group support team would be there to help with any issues that arose with the running of a group, such as venue changes, ideas for speakers or resources to share with groups. They would also be making sure that volunteers received consistent communication and support to deliver their roles.

The Community Development Manager will also be exploring a range of additional ways to offer peer support into the future. That might be things like offering more interest-based support groups like our art group, where people can connect over a shared interest or hobby in an accessible way. Or it might be offering more options to people to join by phone or Zoom, which can be helpful for people in rural areas.

It was important to note that this was in addition to, not instead of, in-person peer support groups.

A member expressed the concern that, although the meeting invitation encouraged attendees to share their views, she felt they had been excluded from doing so at each intervention.

The Chair explained that she would take the questions sent in advance first before addressing any ad-hoc questions in the time available.

A member asked how does the Board currently review leadership performance - are any changes planned?

The Chair responded and said, like many organisations, the Macular Society had a performance management policy, which set out how the performance of all staff was managed. This included an annual performance development review process (PDR).

The Chair undertakes this PDR for the CEO, taking into account feedback from other Trustees. They in turn undertake the PDR for their direct reports, and so on.

No changes are currently planned.

The same member asked how are trustees ensuring the financial sustainability of the Charity? Do they believe they are asking enough probing questions before decisions are made?

The Honorary Treasurer answered and said she chaired the Finance and Fundraising committee which met regularly to scrutinise the organisation's financial performance, and to consider financial sustainability. This included a detailed examination of fundraising performance, of how funds were being spent, and of performance against budget.

The full Board approved the budget, making sure that it was in line with strategy, and at every meeting it reviewed performance against budget and discussed the organisational finance performance together with a report on the fundraising outlook.

This was an area of ongoing focus and attention for Trustees and the Honorary Treasurer said she was confident the Society was adequately challenging and questioning its organisational performance.

A member asked what processes are in place to ensure the proper handling of complaints, or conflicts of interest?

RB answered and said the Macular Society has policies in place for complaints, data protection, and the management of conflicts of interest. The Board receive regular reports on complaints and data protection incidents, and our auditors review declarations of interest from Trustees and senior staff.

Management of these issues is an important responsibility for the organisation which we take very seriously.

The same member asked what is being done to improve organisational culture and staff wellbeing?

The CEO said as discussed earlier, last year was a challenging year for many of our staff.

A staff forum had recently been established and the Society was already talking to members about how best to approach reviewing its culture and what could be put in place to further improve it.

The governance, nominations and people committee oversaw this work and received regular reports on issues like staff turnover and absences.

Two members had both asked how the effectiveness of the new Regional Team Structure would be reviewed following the recent changes.

JK answered and said feedback would be sought from the team, from service users and from volunteers over the coming months. The usual performance measures would also be reviewed to check on the health of the peer support network, including group membership and numbers as well as satisfaction with the peer support offer, which was measured through an annual survey.

Three members had asked similar questions about Trustee involvement in the decision concerning the new organisational structure of the services team, seeking assurance that due governance has been applied to the process.

The Chair answered and said the Board of Trustees discussed the proposed restructuring at our Board meeting in March 2025 and were in support of the proposals before the executive team actioned them, beginning the consultation process shortly thereafter.

Trustees were kept informed of the consultation process and some, including the Chair, were actively involved in responding to members questions about the proposals.

Trustees also discussed and approved the final structure at our December Board meeting. Some trustees also joined the volunteer information sessions describing the new structure, to address questions.

The Chair reminded members that over the time she had been involved with the Society (since 2017), the fundraising team, research team and most recently the finance team had all been restructured. These changes had resulted in a number of staff leaving the organisation as new roles and approaches were created. It had simply taken longer to look at the structure within the regional team.

A member asked whether the Trustees support face-to-face support for Society Members in preference to telephone calls?

The Chair answered and said yes, the Society was committed to offering face-to-face support. Most of the groups met face to face, and the hope was for this to continue long into the future. As the CEO had mentioned, there was a significant community networks team focused on giving volunteers the support they needed to continue these meetings.

However, it was also recognised that face-to-face support did not meet everyone’s needs, and support would always need to be provided in a range of ways. The Society’s approach would always be to meet the community’s needs in the most appropriate and effective way possible.

The Chair addressed the difficulties that Zoom was presenting as a platform for some members, and welcomed proposals for an alternative platform with better functionality.

A member asked a question about whether many of the Society's appeals were being restricted to research, and about fundraising efforts for non-research work.

EM answered and said whilst many of our appeals focus on research as one of the solutions to macular disease, they often contain stories from the people we support to show the impact of macular disease.

The aim was to have as mixed a fundraising portfolio as possible, to ensure that both restricted and unrestricted funds were being raised.

A member also asked whether the regular appeals for donations sent out by the Macular Society almost exclusively asked for money to "beat macular disease" through research. As any donation made to this appeal must be earmarked "research", the member asked what fundraising efforts were being undertaken to ensure the sustainability and development of key activities such as support groups, befriending and counselling that were part of the Society's stated mission.

EM answered and said that the current portfolio, which included legacy income, was largely unrestricted, but the Society was of course using its services to look for restricted funding, both from trusts and foundations and corporates.

A member asked whether Trustees could advise why so many members of staff have decided to join the union.

The Chair responded that it was not possible to speculate on the motivations of staff for joining a union, and indeed the Society did not know how many had chosen to join.

However, the Chair was happy to confirm that the Society had recently signed a recognition agreement with Unite and looked forward to a positive and constructive relationship with the union.

A member asked how long from the initial diagnosis to the beginning of sight loss?

The CEO answered and said this could vary greatly between individuals and there was a need for a much better understanding of the earlier stages of both wet and dry AMD. Dry AMD might be picked up in a routine appointment and could take several years to progress to vision loss. However, wet AMD typically progressed faster, and clinical guidance was to refer within one day of detection and for treatment to ideally start within two weeks.

A member asked is there an update on treatment of wet AMD?

The CEO explained that there were nearly 30 treatments in clinical trials for wet AMD currently, ranging from novel compounds to sustained release systems, gene therapies and eye drops. Many of these were early phase or preclinical stage trials. Some were closer to clinic in phase III but still needed to go through regulatory approval. Vabysmo, high dose Eylea and biosimilars were the most recent entries to clinics, and a webinar on the latest treatments was being planned.

Questions raised in the meeting:

A member queried whether advance questions were being addressed appropriately, and if the comments in the chat were being addressed. She also suggested a further discussion was needed due to the time constraints.

The Chair confirmed that questions that were sent in advance had been addressed and that the comments in the chat were being recorded, and if there was not enough time to address them at the AGM, they would be answered in due course.

In response to one member's point, the Chair stated that the Society's objectives are to both deliver research to beat macular disease as well as to exist to support those who are living with it.

A member queried why there had been no member vote to approve the annual report. The Chair clarified there was no requirement to approve the accounts i.e. to vote on that agenda item.

A member provided feedback on support gaps in local groups, in particular the MMD (myopic macular degeneration) group (with the Chair thanking her and noting an action to address local group gaps).

(via the chat) a member described the vote outcome as a vote of no confidence in current management.

A member expressed concern regarding how he felt members were being treated and suggested that the leadership appeared apprehensive.

A member raised another point of order that referred to compliance with government guidelines. He stated that the Society's governance guidelines required items for discussion to be submitted in advance, not questions, and queried why this had not been followed.

The Chair responded that the organisation was following the guidelines and was addressing both advance and live questions.

The Chair said a member had left a comment in the chat about treatment of wet AMD.

A member stated that members' concerns had not been fully addressed and called for a further discussion and an adjournment of the AGM. Several members indicated support for this suggestion.

The Chair confirmed a commitment to continue listening and invited members to submit their questions to the CEO, whereupon it was proposed that follow up meetings would be held to discuss them.

8. Close of Meeting

The Chair thanked the members, Trustees and staff for their participation and there being no further business the meeting was declared closed at 19:15 to allow the My Macular and Me webinar to commence.

Signed:……

Chair of the meeting