

Minutes of the ME Association Annual General Meeting (AGM)

Held on 9th December 2024

Online Zoom Meeting

Trustees and Associates present online:

Neil Riley (NR) – Trustee and Chairman
David Allen (DA) – Trustee and Vice-Chairman
Charles Shepherd (CS) – Trustee & Hon. Medical Advisor
Ewan Dale (ED) – Trustee
Martine Ainsworth-Wells (MAW) – Trustee
Mike Mitchell (MM) – Trustee
Nicki Strong (NS) – Associate Trustee

Other members present online:

MEA Members who registered
Others with interest in ME/CFS

Note: Questions and answers are a summary containing all relevant content

1. Welcome

NR opened the meeting at 14:10pm and apologised for the delay in starting, due to the overwhelming number of members who wished to join, and then welcomed everyone to the meeting.

NR ran through the agenda, format and housekeeping of the meeting and asked members to limit the questions to just one question at a time to allow as many members as possible to ask questions. Further questions could be asked using the online form on the MEA website.

Before the agenda items – **NR** introduced the Trustees and some of the Team Leaders amongst the staff, who then introduced themselves to the members:

1. NEIL RILEY - Trustee and Chairman-Legal, Governance and HR responsibilities
2. MARTINE AINSWORTH WELLS - Trustee with responsibility for Campaigns and the Media
3. DR CHARLES SHEPHERD - Trustee and Medical Advisor
4. KATHARINE LEAT- Team Leader of ME Connect-our Support and Helpline Service
5. RUSSELL FLEMING - Team Leader responsible for Project Development
6. MICHAEL MITCHELL - Trustee with responsibility for Legal, Governance
7. EWAN DALE - Trustee, responsible for the UK regions in matters relating to ME/CFS
8. DAVID ALLEN - Trustee , responsible for IT services
9. NICKI STRONG - Associate Trustee

2. Apologies

None

3. Minutes

NR asked if anyone had any comments regarding the Minutes of the last AGM, held on the 11th of December 2023.

Members Question: Can you confirm the numbers on the Minutes of the last AGM are correct, that there were only one or two attendees.

NR: Yes, Trustees, Associate Trustees and the Office Manager attended the last AGM, no other members attended even though it was advertised twice in the ME Essential quarterly magazine.

No one raised any further comments.

NR proposed the motion for the Minutes of the last AGM to be approved. ED seconded the motion. All members voted in favour with no objections and the motion was passed.

4. Chairman's Report

NR The Chairman's report for 2023 was available for members to read on the ME Association's website and in ME Essential. NR explained why there is no report for 2024 so far and that the 2024 Chairman's Report will be coming out in the New Year to reflect the whole year and tie in with the Financial Statement, whereas previously, it only covered 10 months.

NR asked if there are any questions regarding the Chairman's Report.

No questions were submitted.

NR proposed the motion that the Chairman's Reports for 2023 should be approved, MM seconded the motion. All Trustees voted to accept the motion. The motion was passed.

5. Financial Report

The Financial Statement, year ended 31st December 2023, was available for members to read.

NR asked if there are any questions.

Members Question Have the Auditors commented on, or have recommendations for, the level of reserves?

NR Yes, it is discussed regularly, the Audit Committee meet every two months, we recognise the reserves are high, and we discuss and show our plans to the auditors and follow their recommendations. The MEA now insists on a full audit, though this is not a legal requirement.

Members Question What were the circumstances for exceptional payments relating to payments to Trustees without the permission of the Charity Commission. Why were those payments paid without authorisation of the Charity Commission? Who approved those contracts and payments? How were the contracts overseen through their delivery, and did the BoT review the guidelines of the Charity Commission?

NR No Trustee in the ME Association is paid for their work as a Trustee. Article 28, you mentioned "In exceptional cases other payments or benefits", look at the word, "other" because "other" is vitally important here, because Article 28 Clause A, regards that any payment as long as it's reasonable and proper, that there's a written agreement between the charity and the person to who it is paid, sets out the exact or maximum amount to be paid. There are 7 different categories there which our charity

abides by totally. We have contracts, including the statements required by the Charity Commission. We fulfill them absolutely fully, and it's only when you get to Clause D that it says, in exceptional cases, other payments, so that excludes the contractual payments for services, and then you do indeed have to go to the Charity Commission.

NR very happy to reply to the member directly on this matter.

NR proposed a motion to approve the financial statements for the year ending 31st December 2023. **CS** seconded the motion. All Trustees voted to accept the motion. The motion was passed.

6. Independent Examiners (of Accounts)

NR We propose the reappointment of Astral Accountancy as auditors of the accounts. At this moment we are looking at other auditors, specialized charity auditors, because the field of charity and auditing is getting more complicated. We are going to look at perhaps bigger companies who have their own special auditing department, the advantage of that is that they can also provide governance and advice.

7. Any Other Business – including questions raised from the community

A. The Editorial and the Editorial Review Process

Members Question: Requesting response regarding the group letter about Neil's opinion piece in the magazine. The official complaint of near to 2,000 people is because we feel the MEA have not taken our concerns seriously.

Members Question: What is the process for reviewing the magazine with the communications team for feedback on tone or content.

- **NR:** I said I love complaints because it gives me the feedback to improve. That's what we want to do. It was very unfortunate those 2 editorials came out like that because I wrote that initial editorial some 4 to 5 months ago, because that's the lead time for our quarterly magazines, and the other one about 2 months ago. The response was not good, but I value all feedback that we get. We will look at everything you've said, and we will try and improve.
- **MM:** I showed the editorial to my wife, an ME sufferer, and she found nothing wrong with it. We don't deal very much with doctors, and we have developed levels of exercise and pacing on our own.
- **CS:** The editorial went in now over 3 months ago, and for I think it was about 2 months we didn't hear anything at all until everyone suddenly got interested when someone put it on social media.
The editorial was really about the role of bed rest and how we use bed rest as part of the management of ME. I think it's a debate which we need to have.
- **NR:** If you look back at the last 10 years of my editorials. The hard stuff has always been with the research, and to try to connect with the audience out there – some I've connected with, and some I haven't. I do my best.
I try to reflect on my "lived life". You may have different "lived lives" from me, some people may have it the same as me.

- **NR:** Yes, we do have other people reading through it, and certainly also the editor of our magazine reviews it as well. If I had known it would have caused all this upset. I would not have written it. It does go through a process of people looking at it. We'll review that process.

B. Chairman

Members Question: Requesting response about the recent change org petition asking Neil Riley to consider stepping down.

- **MAW:** The chairman of the ME Association has already issued a [statement](#) in relation to this topic which we've all seen.
We Trustees are continually appraised of feedback on all kinds of topics all the time, both positive and negative.
The trustees are responsible for running the ME Association and we're focused on delivering to our vision, which is to make the life of people with ME/CFS better by providing information by doing research, by finding the answers.
- **CS:** I'd just like to say I've worked with Neil for 20 years as a trustee, and more recently, obviously as a chairman. I'd just like to pay tribute to Neil. Neil has been the most effective chairman that this charity has ever had, in my opinion. He has devoted hours and hours and hours of his time to keeping this charity going, which, during the pandemic and more recently or less recently, has been very difficult at times. He has dealt with staff absolutely superbly. We are extremely lucky to have Neil as our chairman.

C. Appointing a CEO

Members Question: Running a charity doing any non-exec role is a really challenging task. Could you talk a little bit about your plan to move forward – hopefully you'll be looking at a Chief Executive to come in and people to run the organisation. Let the organisation professionals earn their salary. If you employ the chief exec, they should earn a million pounds a year for you into the charity to help this charity move forward. They will be able to approve any expenditures, because the board of trustees shouldn't be able to approve expenditure to trustees.
There's a lot of support, a lot of intelligent people who can we help you move forward. Such that the ME Association survives for the next 25 years.

- **NR:** They're all very good points. We had a chief executive, and she had a lot of money to play with after the sale of a property and it was spent on staff. Then the money run out, and the association just about went broke. Various trustees stepped in and kept it going, and since that time the trustees, as you've said, have run it. We haven't had a chief executive because we were trying to build the association up. It did not need one, because we had all the skills within the trustee board. In the last few years, the charity has grown enormously. We now have 20 staff, and we have 30+ volunteers. That is getting big, and we recognise that. So, this year we overhauled our organisation. We've given much more authority power to our team leaders. They come to us with budgets and say, we'd like to spend this, we'd like to do that, and we review each request.
About 2 years ago Andrew Miller and Peter White came to us at our office and they made some excellent proposals about how our charity could move forward. It's extensive correspondence that I would be prepared, if they agree, for it all to be published. We talked about recruitment, fundraising and a CRM (Customer Relation Management System). So, we took on a professional fundraiser, and recruiting for someone else to get funds from grants to boost research.

I am standing down from a lot of the hard work that I've been doing over the past few years, and I'm going to look at much more general things, like the legal side, the guidance.

We have not yet decided about having a chief executive. There are various pros and cons to that. One very practical one is finding somebody who is good enough to do it. It's not easy and they can take 18 months to learn the job, and are always after the next job up, then you have to start all over again.

D. Governance and Complaints Procedure:

Members Question: These and other matters could have easily been cleared up earlier with helpful and constructive support. After we copied other trustees in, the matters resolved, resulting in an excellent public statement. This is not the kind of reaction I would expect from a senior trustee, when faced with a constructive and positive motion based on clear evidence, submitted politely and within good time.

And in response to the invitation to us to take this forward, we are extremely ill and have wiped ourselves out trying to communicate this as clear and positive, and be as constructive as possible. You should be trying to make a consulting representative group with market research experts to actually find out what the general ME population thinks

Members question: I contacted the MEA in early November asking for deadlines and format requirements for the motion that I wanted to submit. Replies seem designed to delay, confuse and ignored repeat requests for discussion about our motion to take place in a way that recognised our cognitive dysfunction. The tone of the communication seemed designed to catch us out on minutiae. For example, miswording pretty much invalidated our motion and we were only told this after the submission deadline had passed, delayed because of your request for a zoom call when we wanted to communicate in writing.

- **From Post-AGM statement:** We will undertake a review of the Governance of the MEA. This to include consultation with our members, especially of those with Severe ME (facilitated), but also to seek advice from and to consult with all relevant organisations and bodies within the charity sector. The aim to ensure that the MEA continues to follow best practice in all its activities. We will report to Members by the next AGM. We intend to become more transparent about what we are spending our funds on in 2025 and are developing a year-round communications programme informing you, our Members, about what we are doing.

E. Succession Planning and Trustee Appointments

Members Question: Raising the consequences of having insufficient renewal of trustees over 2 decades. Any organisation needs to have adequate succession planning. And an assessment of the need for additional paid staff to undertake much of the work that trustees have been doing free on behalf of the organisation because we need to pay them professionally to do that kind of work, we believe. And that the community gets regular democratic transparent updates on the progress of this work.

- **NR:** We have been in correspondence with you and would like to discuss your proposals with you, because we want to improve. As always, and we've looked at the Charity Governance Code very carefully, it says it is deliberately aspirational. We want the code to be a tool for continuous improvement towards the highest standards. We think you can help us do that, and we're very open.
- **NR:** People don't realise what a charity like this, or many charities have difficulty in finding trustees. It is a very difficult task and take our charity. Our trusteeship is, it is quite demanding, because we bring our skills to run the organisation. But we always welcome applicants. There are organisations that will provide independent trustees from outside

the sector. So that's something we can look at as well. We have six trustees at the moment we're allowed eight as a maximum, so there are two vacancies if any of you would like to come.

- **Post-AGM statement:** We advertise beyond our Membership for Trustees and will continue to do so and are open to applications to supplement the tremendous capability and experience we have across legal, information technology, marketing and communications, medical, scientific and business.

F. MEA Social Media Community [Policy](#):

- **NR comment:** Social Media is a wonderful tool. It's enabled all of us to join together into communities.
I've been on the very unfortunate end, and many of my trustees have as well, from comments that have been abusive. That have really attacked our professional ability to do the job. It's been very tough indeed for myself, my fellow trustees and the staff at this charity.
If only people would carry out the communication that many of you have shown today which has been in the main supportive. We are always willing to talk.
- **NR:** Don't let's have big arguments out on social media. It's great to have this constructive discussion. That's what will help us grow and make this charity even better than it is at the moment.

G. AGM Notice

Members Question: to make the notice more prominent in future, with more notice, and to publish the notice on social media

- **NR:** Certainly, I'm delighted there are so many here today. We do advertise it. We have advertised it in the past. And nobody has come over the past 10 years. I think the majority of the members we've had about 20 over all those years, but there are so many reasons for that, and we wish people would take more interest in us.
- **MAW:** Yes, we need to do more in the future to ensure it's more prominent.

H. Forum for Severe ME

Member Question: I think particularly people who are severe, and very severe, need more representation, and a channel by which we can feed back to you the debates about bed, rest, and deconditioning. I think a discussion where we pool ideas and we merge them, and we find, what do we have common ground

- **NR:** I certainly think that can be done. I've made a note.
If you'd like to get in touch with us through a contact form, say, and just say we'd like to set up a panel. And then those who'd like to join it who are here today also write in, and then we'll try and assemble you all together. You will be able to run it, decide, and then come to us with feedback.
- **CS:** We work quite closely with the 25% group who obviously specialise in dealing with people with severe ME on a number of issues and matters. I don't know whether you are part of them.



I. Communication with Members

Member question: There is a real need to improve communication between the team at the ME Association and the membership. The motion has done us a great service, because it's brought this issue to the fore. Of course, it must always be conducted with courtesy and consideration on both sides.

- **CS:** I am on Facebook morning, noon, and evening, answering questions from people 7 days a week quite often. Followed by discussions, sometimes involving, up to 100 different comments. Our social media is extremely active.
- **Emma Jeffries - Communications:** I'm open to everything that you're saying, and in 2025 I've have big plans.
I'm always open to have a chat. I'm here if you want to email me.
- **MAW:** Our communications team have been absolutely 100% focused on getting out information which is about support. Whether it be about diet and treatments, enhancements, etc.

Positive Feedback received:

- A massive acknowledgment of the work, put in over many years by many people and we absolutely herald that, and a big shout out to all of the staff and the volunteers who work at the MEA. We are totally grateful for everything that people have done.
- The ME Association does an amazing job.
- I think the MEA has done a lot of good, and that's brilliant.
- I think the majority of people see the fantastic work the team have done over the years and the power and energy you put into it.

NR thanked all those for attending and closed the meeting at 16:30pm

Signed

Dated

Neil Riley
Trustee and Chairman of the ME Association