

Minutes

Minutes of the AGM held on 24th March 2018. 3.00PM.

Present: Mark Leverington (ML), Russell Wheeler (RW), James Ferguson (JF).

Also in attendance: 10 members (list attached).

Agenda:

1. Minutes of the 2017 AGM
2. Trustee Report
3. Election of Trustees
4. 2018 Patient Day
5. LHON society strategy
6. Society Communication Policy
7. AOB

Agenda Item #1

Discussion: The meeting unanimously agreed that the minutes the 2015 AGM were a true record of the meeting and they were accepted without modification.

Agenda Item #2

Discussion: Secretary of the society ML discussed the Trustees Report and outlined the constitutional change adopted at last year's AGM which recognises the remote location of many members when it comes to arranging formal meetings. The society raised £873 in income during the past year entirely from fundraising activity and donations. There were no expenditures during the year and this results in a closing balance in the society's accounts of £7,990. However, it was pointed out by the secretary that as our financial year end is May these accounts do not incorporate the costs and revenues associated with the annual patients meeting held later in the year and these will be accounted for in the 2018 returns.

Agenda Item #3

Discussion: Mark Leverington retired as a trustee by rotation and offered himself for re-election. It was unanimously agreed to re-elect Mark as a trustee of the LHON society.

Agenda Item #4

Discussion: ML explained that we have had a generous offer from Cardiff University to host our 2018 patient day at their premises with minimal costs involved to the society. This is a welcome move as the last event held in Cambridge was a major undertaking with substantial costs involved and the trustees consider that it is unsustainable to host an event on that scale every year with our current level of support. Hosting the event in Cardiff would also

fulfil our aim to reach as many members in the UK as possible and not be seen as an exclusively South East based organisation.

Hosting the event in Cardiff also provides an opportunity for us to showcase some new speakers to our members, including Professor Marcela Votruba who is a leading clinician and researcher in the field of LHON. This may also facilitate a change of format in an attempt to be more inclusive so that our members become more than just an audience for words from the podium and we have asked Lydia Harper from Cardiff to help us in this process.

There was a small discussion about the use of the term "Patient Day" to describe this event and it was acknowledged that this term is off-putting to some. "Conference" was felt to be too stuffy and "Conference and Family Day" was proposed as a compromise, which will be considered by the planning committee for this year's event.

Agenda Item #5

Discussion: RW spoke in a little more detail about some of the activities undertaken over the past year which are outlined in the annual report, in particular the work done by the society in support of the Scottish Medicine Consortium's assessment of Raxone in treatment of LHON. The society's submissions as part of this process were fundamental to the approval of Raxone for prescription in Scotland and this represents a clear purpose for the society. A similar exercise is likely to be undertaken by NHS England during the current year and the society will again provide support and consultation.

RW pointed out that this is inevitably a boring topic but one that is crucially important for our members. Not only Raxone (Idebenone) but all future treatments including gene and stem cell therapies will need to go through the regulatory process and if they are rejected then they will not be available to our members. It is far from impossible that a cure for LHON is discovered but only the very wealthy will be able to benefit if it is not approved and funded by the NHS. We cannot sit passively and assume that governments will always do the right thing when we can see that this is often not the case.

The focus of the society's strategy has in recent years shifted much more towards this type of activity and towards research into the causes of the condition and possible treatments. As a small society we cannot do everything and, given the outstanding support provided by many other organisations dedicated to helping those with visual impairment we should wherever possible guide our members towards those services wherever possible and appropriate. That does not mean we will not continue to counsel and support our members where we can, but our focus is much more towards research and regulatory issues and we need to communicate this more effectively.

Agenda Item #6

Discussion: JF attended a conference on rare disease advocacy only the previous week where the workshops on social media strategy stressed the importance of sending a clear message and reinforcing it over and over again via a fully thought out communication strategy. It was acknowledged by all that as a society we have not scored well in this area and agreed that as a matter of urgency we need to review our strategy and make a concerted effort to communicate our aims. Josie Atherton agreed to join a newly formed communications team and after some support and training to take over the society's Twitter account, which has only been used sporadically so far and without any clear policy for how it should be managed.

Agenda Item #7

Discussion: The following comments mostly took place during the discussion of agenda item #4 and to a lesser extent #5 but have been moved here in the minutes as they are more general in nature and stemmed from conversations about the meeting but have a wider context also.

There was a prolonged discussion about the relative lack of engagement among the membership in the activities and aims of the society. Matt Leverington suggested this was at least in part due to the reality that there is no cure at present and consequently many people concentrate on other aspects of their lives. While this is in many ways a healthy attitude, we need to do a better job of communicating why there is more reason to engage than our members realise.

Equally, there was puzzlement about why many UK members of the LHON Society Facebook group choose not to join the society formally despite personal invitations to do so and our policy of not charging for membership. Richard Wheeler suggested that one reason might be that although the signing up process has been made as accessible as possible, some potential members may still find the process challenging and we should consider a telephone helpline to assist people to sign up for membership. This could be run on a voluntary basis perhaps using Skype or similar technologies to keep costs low and allow for a rota system to provide support.

The formal meeting was closed at 5.15PM after which those present retired to a nearby pub and restaurant to continue discussions.

Members attending:

James Ferguson
Karen Leverington
Lee Leverington
Mark Leverington
Matthew Leverington
Russell Wheeler
Josie Atherton
Joan Atherton
Rhiannon Wheeler
Richard Wheeler
Alethea Wheeler

Members attending by proxy:

Paula Hill
Yacine Zekri