



## Minutes

Minutes of the AGM held on 7<sup>th</sup> January 2017. 4.00PM.

Present: Mark Leverington, Russell Wheeler, James Ferguson.

Also in attendance: 26 members (list attached).

## Agenda:

1. Minutes of the 2015 AGM
2. Trustee Report
3. Election of Trustees
4. Amendment to constitution
5. LHON society strategy
6. 2017 Patient Day
7. AOB

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### 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:** Mark Leverington discussed the Trustees Report and also provided an overview of the membership status to date. Society funds are currently just over £7000 and have come exclusively from donations. Membership currently stands at 198 members. Approx. 75% of these are UK members and 45% are affected with LHON. The rest of the membership is comprised of family members, friends and a few researchers. There is no charge for membership and no restrictions for eligibility.

### Agenda Item #3

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

### Agenda Item #4

**Discussion:** Russell Wheeler outlined the proposal to amend the LHON society constitution and the reasons why the trustees felt this change is necessary. It was unanimously agreed to change the constitution so that a quorum of general meetings shall be the greater of 2.5% of the membership or 10 members.

### **Agenda Item #5**

**Discussion:** Mark Leverington presented a draft copy of the LHON society vision, priorities and strategy. There was a brief discussion around some of the priorities identified in the document: the importance of patient registries for rare diseases and the value of social contact within the LHON community for those affected and their family.

### **Agenda Item #6**

**Discussion:** Russell Wheeler provided some brief details of a planned LHON Patient Day in Newcastle on 24th June 2017 and asked those present for their views on the format and name of this event. Although last year's Patient Day had been received very positively based on the survey feedback, a few members had voiced concerns on the use of the term 'patient' in the event name. James Ferguson and Matt Leverington agreed that some people may be discouraged from attending by calling the event 'Patient Day'. The trustees agreed to consider the various suggestions for the event name and format provided by members present at the meeting.

### **Agenda Item #7**

**Discussion:** Russell Wheeler provided a summary of a request by the Scottish Medicines Consortium (SMC) to the LHON society to make a Patient Group Submission to support the SMC assessment of Raxone (Idebenone) for use in NHS Scotland. There was some discussion around the information for patients provided by Santhera and the requirement to survey the membership for this submission but due to meeting time constraints, the trustees agreed to continue the discussion via email and Skype.

The meeting was closed at 5.15PM

Members attending:

James Ferguson  
Emily Leverington  
Karen Leverington  
Lee Leverington  
Mark Leverington  
Matthew Leverington  
Russell Wheeler  
Brenda Leverington  
Sophie Chambers  
Mike Smith

Members attending by proxy:

Denise Chambers  
Yacine Zekri  
Andrew Keil  
Craig Leverington  
Paula Hill  
Daren Hill  
Jojo Sanders  
Carl Morrison  
Lynnette Ferguson  
Ronald Zammit

Rhiannon Wheeler  
Richard Wheeler  
Sam Wheeler  
Elli Posch  
Harvey Susser  
Cleo Susser

Apologies:

Ian Ketteringham  
John Skyner  
Brian Cranson  
David Williams  
Derrolyn Laslett  
Chloe Laslett  
David Laslett