

The Members' Annual General Meeting was held on 28 October 2017 with a small attendance, at Thorseby Hall Hotel near Ollerton, Nottinghamshire.

Chris Fuller had received correspondence raising a number of concerns following the receipt of the annual report and accounts which may answer members questions on how the charity is moving forward.

Concern: The full accounts were not available in the proper format prior to the AGM – was this a concern to the Board?

Answer: The accountants were well aware of the AGM deadline and the Board was confident that they would be available for the meeting. The trustees meet quarterly, and the treasurer produces a quarterly statement of the charity's financial performance for the Board. So, at all times the trustees are aware of the charity's financial performance, plus of course the AGM gives the members an opportunity to see the financial position and raise any questions on the figures with the treasurer.

Concern: You are proposing to spend some of the accrued funds on purchasing a property. It means that the Charity will be rooted to one locality which future Boards might find inconvenient. It also means that we will lose the opportunity of spending more money on the objectives of GAIN.

Answer: The decision to purchase our own building was driven by a number of factors. These include the charity has outgrown its current premises in that the meeting room is too small for trustee meetings, our current lease ends in 2020 and we have had a number of legacies meaning cash distributed across a number of bank accounts earning interest below the rate of inflation thus slowly diminishing in value. The advice of our accountants was to invest into property which of course has the benefit of saving on year on year rental costs as well as giving more space to develop events for members or for our fund raisers. Such a move does of course firmly secure the long-term future of the charity and avoids the risk of having to rely on landlord goodwill in the face of rising office rental costs. What will become a fixed location is not seen a risk to the operational capability of the charity. It has since inception been located in the Sleaford area and as a national charity covering the UK and Ireland then, within reason, any site is as good as another. However, in Sleaford we have the key advantage of experienced staff and a move elsewhere would mean a loss of that expertise with damage to the charity's operations. As to your point about instead spending the money on the charity's objectives, I'll cover research in the next paragraph. In terms of our other aims, the report covers those but in summary we are increasing the assistance given to families of patients, researching other areas into which we could expand the range of that support, engaging consultants to improve the usability and content of our social media coverage as well as supporting the use of drama to increase the awareness of GBS.

Concern: In the abbreviated accounts there is no mention of expenditure on research. Obtaining funds for research into a rare disease such as GBS or CIDP has always been difficult and GAIN has in the past supported excellent research in Glasgow and elsewhere. Registers such as IGOS for GBS and the new registers for CIDP promise to make real advances in our understanding and treatment of them but need funding which is not readily available from government or generic charities. We may be on the cusp of discovering new treatments for GBS and related diseases with complement inhibitors which will make fundamental differences to people with GAIN conditions. It is only research which will lead to advances which will make a fundamental difference to the outlook for GAIN patients.

Answer: In terms of research, the report shows we are working with researchers to help them obtain feedback relevant to their research area from patients and ex patients. We are also in dialogue with the Medical Advisory Board (MAB) about the best way of funding a

research student over a one to three-year period in an appropriate area of research. The charity has recently supported two research projects, one in Glasgow and one in UCL, where we are awaiting the final reports. We are about to support another study with patients several years post GBS.

Concern: The number of voting members is declining

Answer: In common with other charities, the number of members is indeed falling and has been doing so for the past five years. In the wider social context, we are finding that how people choose to engage with the charity is changing away from a more formal context than has been the case in the past increasingly towards the use of social media to obtain or share information. The number of people that we are helping, both directly and indirectly is increasing with around 4,000 people on our database. But we are not ignoring those who prefer a more traditional way of obtaining information. We are commencing to rewrite our information booklets in a clearer, more up to date format ensuring of course through MAB that the content is correct in terms of the medical content.

Concern: The tradition of holding an annual educational and supportive meeting for members has fallen into abeyance.

Answer: It was agreed through a membership survey that events would be held every two years. However, in 2014 we had to cancel an event because of insufficient attendees and in 2015 as well as 2016 we have struggled to get sufficient attendees at events to make a quorum, even at the Glasgow centenary event. No event was scheduled for 2017 and we are planning for an event in 2018 but the reality is, as said above, people are changing in the way that they choose to engage with the charity. I suspect that increasing family commitments as well as increasing costs are also a factor regarding national events.