

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
28th November 2024, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH), John Mason (JM), Mitesh Patel (MB), Estelle Marshall (EM), Helen Payne (HP) Michael Payne (MP)

Apologies: Mike Cain (MC), Juan Vasquez Ruiz (JV)

1. Introduction

AL welcomed thanked all attendees and welcomed Estelle, Helen and Michael to their first meeting.

2. Policy review. –

AL opened the discussion and we had reviewed and approved the Data Processing Framework and Confidentiality Agreement, both suitable for 6 year review.

It was decided that the process was too lengthy to complete the other items this way, so Trustees were asked to review the:

- Code of Conduct
- Register of Interests Policy
- Gifts Policy
- Control of Minutes
- Our mission statement

individually and respond back to Adam by mid-December so that the could finish the action.

JM would provide a further re-draft of the Expenses Policy to accommodate the points discussed.

3. Committee Review

It was agreed that some changes were needed to the working of our committees:

- The Helpline Committee was now thought to be redundant and should be deleted from the committee list
- There was a need to refresh the Research Committee. EM volunteered to join this group.
- The Newsletter committee also need to be refreshed, Helen Payne volunteered to join it.
- The Fundraising Committee needs work as well. Suggestions from the meeting were to see if some of the members who had raised funds might join: Tom Bell and Jason Main were suggested as possibilities. AL would follow up.

4. Updates Treasurer, Membership, Secretary

Treasurer - JM reported £124K in bank. A savings account had been opened and £100K had been transferred into it. There were no questions.

Secretary - DH reported five Grant Applications since last report in May. Four Approved, one rejected – less than two years since last grant. Forty one Contact Forms over the same period with a similar number of “Spam” type messages.

Membership Secretary - MB reported current membership total to be 399, there having been nine new joiners since his last report.

Chairman - AL had uploaded two AGM presentations on YouTube, with a third still due to be loaded. Several persons had volunteered to help the group. AL was still checking and discussing with individuals. Pippa Lee had volunteered to take over the Newsletter editor role.

5. AOB.

a) Estelle asked about progress with her Information Sheet. Adam had not had time to review it but asked that it be re-sent and he would progress it.

b) Siang Ing Lee is involved in work where information is required about developing improved genetic testing for HSP. The team she was working with wanted to know if data from HSP group members might be used to help this development. After discussion it was agreed that there was no objection in principle but there would be a need to protect confidentiality. There would be a need to update the database to include the type of information needed. It was also observed that many members did not have the information, not having had genetic tests. If this "patchy" information could be suitable for the proposed research there was no objection to moving to the next stage.

c) A membership location Scattergram update had been requested. After discussion it was agreed that it was only appropriate to publish a fixed scale (non-zoomable) A4 sized version on the web site. This was to ensure there was no way to identify individual members/ locations from any data within the map.

d) Member Pippa Lee was proposing to produce a booklet about HSP aimed at younger people. She has provided an outline of the intended contents and an estimate of the cost to get it printed and published on-line. The cost was estimated to be about £3,200. Trustees considered this to be a worthwhile project and were generally supportive. EM offered to contribute to this effort if required. AI would discuss with Pippa.

There being no further business, the meeting concluded at 21.00.

Agreed by email as an accurate record on 13 December 2024.