

HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP
Registered Charity No. 1181539
Trustees Meeting – [Online Meeting].
11th September 2024, Start time 19:00

Minutes

Attendees: Adam Lawrence (AL), Dave Harris (DH), Mike Cain (MC), Juan Vasquez Ruiz (JV), JohnMason (JM), Mitesh Patel (MB), Estelle Marshall (EM), Helen & Michael Payne (HP, MP)

Apologies: None

1. Introduction

AL welcomed everyone to the meeting and stated that he wanted the meeting to discuss two main items:

- a) An outline plan for the best way to wind up the charity if we were unable to conduct our business properly.
- b) Succession Planning – working out how to fill outstanding Trustee vacancies to ensure the continuation of the group.

2. Wind-up Planning. –

AL opened the discussion and listed four ways which he saw as possibilities:

- a) Merging the HSP Group with another appropriate charity
- b) Distribute cash assets to Research Teams
- c) Donate assets to international HSP Support Groups or groups like the Neurological Alliance
- d) Donating/distributing to other smaller groups with an HSP focus.

JM/DH had each been considering distribution of assets to HSP Group members. Both had separately concluded that this approach quickly became too complex to reach an equitable conclusion.

Another suggestion was to get Research Groups to apply for monies in advance of their work.

After general discussion, the most satisfactory approach was deemed to be inviting the membership to apply for grants, and after this getting bids from Research Groups so as to distribute the rest.

3. Succession Planning

After some generalised discussion, EM offered to become a Trustee, HP offered to take up the editorship of the newsletter and MP offered to take up the role of Trustee/ Treasurer, having been a qualified Accountant.

AL would talk with individual after in the near future to clarify matters and get the necessary form to be completed.

Actions: AL would chase up other possible volunteers to see if they still wished to offer their services. AL would also draft a “Letter to Members” to update membership on the changes which were to be made.

4. AOB.

EM very much wanted to use her physiotherapy skills to help our members as much as possible. Opportunities for Zoom type sessions and /to to develop appropriate videos restricted to membership were highlighted as possibilities.

There being no further business, the meeting concluded at 20.17.