HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539 Trustees Meeting – [Online Meeting]. 24th November 2022, Start time 19:00

Minutes

1. Attendees: Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Mike Cain (MC) (technical issues prevented participation), Emily Bell (EB).

Apologies:

AL opened the meeting and stated the main purpose which was to consider the coopting of three Trustee candidates.

- 2. The Candidates were considered in turn:
- Shanake Amarasinghe after discussion by the Trustees there was agreement that Shanake should be co-opted as a Trustee and should continue to "shadow" the Treasurer.
- **Craig Hargreaves** after discussion by the Trustees there was agreement that Craig should be co-opted. No decision has been made on what role he might take up.
- Kolade Olaiya after discussion by the Trustees there was agreement that Kolade would not be co-opted, there being insufficient confidence that he suited the role.
 AL will seek appropriate email addresses for the co-opted persons and notify committee so we can introduce them into email lists.
- 3. Any other business
 - a) AL had five topics for which he wished to give a brief update:
 - An Australian student has produced an essay which was part of the Student Voice competition run by Beacon (formerly Findacure).
- Tony Hart is about to undertake a study in Sheffield supported by a student looking at childhood HSP. We will inform members about this by e-mail.
- AL had done a presentation at work about HSP and we would be receiving a donation from Atkins as a result.
- The three students involved in various current exercises had been offered honorary membership and all had accepted.
- A further research Grant Application from Evan Reid at Cambridge is being considered.

 b) DH provided a short update on the Mehmet Komesogutlu Jnr Grant Application. We now await a revised cost for this application as it was clear that the original application had not taken ancillary cost (installation etc) into account. Trustees raised no objection to this approach.
- c) It was agreed that a further trustee meeting should be arranged in late January 2023.
- d) DBS Checks Mitesh agreed to look into the DBS check process and advise trustees
 of what was needed.

There being no further business, the meeting concluded at 19.25.