

# HEREDITARY SPASTIC PARAPLEGIA SUPPORT GROUP

Registered Charity No. 1181539

Trustees Meeting – [Online Meeting].

24th August 2021, Start time 20:00

## Minutes

1. **Attendees:** Adam Lawrence (AL), John Mason (JM), Dave Harris (DH), Mitesh Patel (MP), Mike Cain (MC).  
**Apologies:**
2. **Previous Minutes** Version 1 of the minutes had been circulated on 17<sup>th</sup> of July and were accepted as correct.
3. **Meetings – face to face.**  
The Covid situation was still very fluid, but many events were now going ahead. Trustees agreed to allow face-to-face meetings with the following three recommendations to organisers: attendees should take a lateral flow test before attending a meeting, wear a face mask at meetings and maintain social distance at meetings.
4. **New Trustee update.** After further thoughts, the member who had considered joining the Trustees has decided not to proceed further. We have no outstanding volunteers now.
5. **Sheffield grant application payment** Trustees had a lengthy discussion about the situation and most felt there was insufficient justification for paying for two years funding when no student had yet been recruited. We were happy to reinforce our original offer for four years which had been “tied” to the recruitment of a student to pursue the project we wished to support.
6. **Registry update** No firm ideas were yet in place for further development of the idea of a national registry of persons with an HSP diagnosis. Several approaches were being considered. Issues around privacy, security and commercial value had to be taken into account as these may well affect the practicality (e.g. level of security required for server hosting). **AL would produce a brief summary of the purpose of such a registry to help in defining a way forward.**
7. **1000 miles update**  
More than 20 members had contributed distances so far and the original target of 1000 miles had been reached. We were now considering continuing back to the start at Lands End. If Gift Aid is taken into account we have already passed the initial funding target of £5000! It would be good to get more members involved and publish their associated stories.
8. **Paralympics** A drew attention to the Paralympics which start tonight. At least seven athletes were identified as having HSP:
  - Ian Marsden in Team GB in canoe,
  - Austin Smeenk in Team Canada in athletics,
  - Toni Ponce in Team Spain in swimming,
  - Evan Austin and Hallie Smith in Team USA in swimming,
  - Rebecca Hart in Team USA in dressage,
  - Roman Polianskyi in Team Ukraine in rowing.
9. **Website committee** AL had asked MC to produce TOR for the website committee. AL had not yet had time to review the points listed. JM felt that much of the terms of reference were included in our already published HSP Committee Structure document. We also need to select someone to chair this Committee.

**10. AOB**

a) MC asked how blog entries could be put on the web site. AL asked that items be forwarded to him for publication. .

b) HSP Research Award – AL had been sent eight papers which were competing for the award. A condition of being one of the judges was that he was under a non-disclosure obligation re the names of candidates, but he could discuss the papers themselves.

There being no further business, the meeting concluded at 20.55.