

HSP Support Group AGM 2021 – Trustee Statements

Trustees for the group need to be elected by members. This is done by a majority vote at the AGM. The minimum number of trustees is three, and the maximum ten. Under the constitution trustees are elected for a three year term. Mike Cain was elected at the 2018 AGM and has decided to stand for election again.

Mike Cain

I am the only trustee to be nominated by the individual members and I have tried consistently to represent your views in the opportunities I have been given.

As a group, we are members of Genetic Alliance and through them I have been given the opportunity to raise the awareness of HSP and peoples needs in Westminster, Edinburgh and Welsh Parliaments, and I have Zoomed with Northern Ireland contacts.

I have used other connections I have developed over years to help the search for a cure and the spread of knowledge of people's needs amongst trainee doctors and researchers and linked these into other trustees.

As a member of the Research Subcommittee, I have been involved in spending our money, to date mainly we have spent it on research in UK, and it is not clear how information and healthcare collaborations that currently exist will continue.

As a member of the Meetings committee I worked with Irena to move the St Helens meeting to Stockport and have had a couple of meetings at Morecambe whilst we continue to look around Preston for a suitable venue, so please suggest any ideas. I have also looked for a place in North Yorkshire and have settled on Malton. Newcastle came as a result of my association with the University there and I am now pleased that we have set up a Zoom meeting in Scotland. While a physical meeting was planned in Stirling, we were overtaken by the pandemic restrictions and it is beginning to look as though the one Zoom meeting will be replaced by three physical meetings to reflect where people are. We also had a small meeting in Belfast while I was on holiday there.

Looking to the future, we need more helpers to continue raising awareness in UK. People as meetings organisers with local knowledge where might be suitable, and people who are willing to be trustees. We may get help to expand our membership. We need to increase awareness amongst professionals, and it may be that we meet funders who would be prepared to help organise such a meeting.

Of the meetings I have attended through Genetic Alliance and my outside contacts, potential funders and independent people have indicated that we need a larger and more representative database. GA have established a group to explore how larger, well funded charities can share resources with smaller ones like us and I hope to have an update on that soon.

We have found that HSP databases are different depending where in the world they are based, and one of the Scottish members has suggested that we have a database, and another is investigating how this can meet national guidelines. Other patient groups seem to have these. There is no single database that represents the incidence of HSP in the UK and how data is shared or not with the various NHS services (England, Wales, Scotland, N Ireland)

So, if you vote for me, I will continue to build awareness and spend our money as you wish, and serving where our chair and I think my services can be best used.

I am happy to answer any questions you have.