

HSP Support Group AGM 2023 – 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. Adam Lawrence and Mitesh Patel were elected at the 2020 AGM and have decided to stand for election again. The trustees have also appointed Shanake Amarasinghe and Juan Ruiz as trustees, and they stand for election for the first time.

Shanake Amarasinghe

I was introduced to HSP by my friend of 15 years Mitesh Patel.

It would be an honour to contribute to the good work of HSP in the role of Treasurer.

Adam Lawrence

I am honoured to have been Chair of the group since 2017. I enjoy working with the trustees and everyone helping the group move forward. I am really pleased with and proud of the progress that we continue to make with the organisation of the group, and the benefits we deliver to our members and the wider HSP world.

If re-elected as a trustee I will continue to build on the progress made helping us to work in a consistent, transparent and supportive way. I will strive to; continue capturing best practice and sharing it with others, make our information easier to find, and help people to be more connected and able to help themselves.

I will continue to listen to members to find their opinions of, and ideas for, the group. I have stated these aims in my previous trustee statements, and they are still relevant. I would like the group to:

- give better support to those whose journeys are more challenging,
- coordinate and support fund raising activities,
- begin to steer the direction of HSP research in the UK,
- develop links with relevant organisations so we can collectively help each other.

Mitesh Patel

My partner has HSP. I have seen first hand the challenges with everyday tasks and decisions but also been privileged to see my partner complete medical training and become a doctor. This can inspire others. I hope to support those with HSP, family members and impart my medical and research knowledge.

Juan Ruiz

Since our daughter's diagnosis in 2020, both my wife and I have been trying to learn as much as possible about HSP. We have had informal discussions with research teams, joined facebook groups, and sought out people also affected by this condition. We are very grateful for all the help we have found (and are finding) along the way, from thoughtful physicians to patients eager to share their knowledge. We have been impressed by the work this support group has conducted to date, especially when it comes to supporting UK-based research on HSP. As an example, the work supported by this group at the University of Exeter gives us hope that progress is being made towards a cure. I would like to help in furthering this research. I do not have any clinical or research credentials, but I do have a strong vested interest in this condition, good organisational skills, and the willingness to take on any projects that might be conducive to any amelioration or hopefully even the reversal of HSP symptoms, especially in children. I look forward to learning more about the Group's activities and how to best contribute to them. Thank you very much for your time.