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www.panspandasuk.org
Charity No: England – 1178484 | Scotland - SC053206

PANS PANDAS UK Community Reference Group

Terms of Reference

Group Name

PANS PANDAS UK Community Reference Group

Type

An advisory group comprising individuals with lived experience and insight into PANS and PANDAS. Members bring valuable perspectives that help enhance the charity's understanding and approach.

Accountability

The group is accountable to PANS PANDAS UK.

Purpose

To strengthen engagement between PANS PANDAS UK and the wider community by:

- Sharing updates and information
- Gathering feedback
- Encouraging collaboration and co-creation.

Responsibilities

Members may:

- Provide feedback on the charity's activities
- Suggest ideas and improvements
- Share personal experiences and insights, when relevant.

Authority

This is a non-decision-making advisory group. All input is valued and considered, but final decisions rest with the charity.

Membership

- Open to parents and caregivers of children or young adults affected by PANS or PANDAS, and to individuals who are personally affected.
- Members can join or leave the group at any time by emailing info@panspandasuk.org.
- Participation is flexible - members can engage with projects that resonate with them and opt out of others.

Updates and contact

If you provide consent, we'll add you to a WhatsApp announcement group which will enable us to quickly share upcoming projects and opportunities with you. No pressure, just updates when they happen.

Contributions

We anticipate that members will be invited to contribute in a variety of ways, including:

- Completing surveys
- Offering feedback
- Consulting on various projects
- Co-creating resources
- Occasionally attending meetings if required – these will be held online, via Teams.
- If meetings are required, invitations will be sent two weeks in advance, with an agenda and joining instructions shared one week before.
- Meetings will be recorded for minute-taking only, and recordings are deleted once minutes are finalised, in line with GDPR.
- Minutes will be shared with those present at the meeting.

Meeting Guidelines

Please help us create a respectful and inclusive space by following these principles:

- Mute microphones on entry.
- Use chat or hand-raise feature to ask questions.
- Respect all voices and experiences.
- Avoid criticism of individual professionals or political commentary.
- No screenshots, photos, or recordings allowed.
- Do not share group content externally without permission.
- Protect children's privacy - avoid using names and seek consent if sharing details about children over 12.
- The Chair will ensure all voices are heard. If time is limited, the chair will prioritise those who have not yet spoken.
- Repeated breaches of these guidelines may result in a request to moderate behaviour or leave the group.

Reporting

- Minutes are shared with the Senior Leadership Team.
- A summary is included in quarterly reports to the Board of Trustees.