

Norrie Disease PPIE Group

The GOSH research team are hoping to recruit members of our community to a new Norrie Disease PPIE group. PPIE stands for Patient and Public Involvement and Engagement, and PPIE groups are a fantastic way for people with lived experience and key stakeholders in our community to be involved in designing and shaping the research that is happening in Norrie disease. **If interested, email: j.arwyn-jones@ucl.ac.uk**

What is involved?

We aim to have an initial meeting in early 2026. This meeting will be held online to cover what is expected from the PPIE group and to give an overview of our current studies and future planned studies.

At a second meeting in mid 2026, we will aim to inform the design of our ongoing and new research projects. This will involve reviewing our research plans and research documents. In particular, we would like the PPIE group to provide input in reviewing an audio-described patient information video that we are making about the work in our lab. This would require the members of the PPIE group to review a script for the information video, and come to a meeting with feedback points. Meetings will be recorded for us to use the information gleaned in our project design.

From then on, we will host regular once or twice-yearly meetings to contribute to the ongoing conduct of our studies. This will enable agreement on the scope, processes and activities to ensure the projects are relevant and their outcomes are clear. It will also ensure that any methods proposed are acceptable and sensitive to the situations of participants. It will again involve the review of research reports and updates.

Towards the end of our projects, the PPIE group will play a pivotal role in the dissemination of results, including the co-development and review of documents designed for patients.

Who can be involved?

We are looking to recruit up to 6 people with an active interest in shaping our research. This may include patients with Norrie disease, their family members, or people with an interest in Norrie disease, hearing loss, hearing treatments, and research areas related to this. We would like to include young people where possible too.

Feedback

Members of the PPIE group will receive feedback on their contribution within the month after each meeting, as this is highly valued by members of PPIE panels in other projects.

Accessibility

It is our job to ensure accessibility and every meeting will be planned in detail with this in mind.

Expenses

All reasonable expenses will be covered in full by a dedicated PPIE budget within our project funding. This includes travel, as well as remuneration for your time, such as time spent reviewing documents.

If interested, email James by 31/03/26: j.arwyn-jones@ucl.ac.uk

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