



Hope for families with life-limiting epilepsy

DSUK Lived Experience Board Handbook

This document explains what being a Lived Experience Board member involves, what you can expect from Dravet Syndrome UK (DSUK), and what DSUK asks of you. We are grateful for the expertise and support of our Lived Experience Board members, who give their time on a voluntary basis.

About the Lived Experience Board

The Lived Experience Board brings together families and carers affected by Dravet Syndrome to help inform and shape DSUK's family support services to advise and support DSUK in understanding the needs, priorities, and experiences of families. Your insight will help ensure that DSUK's services are relevant, accessible, and responsive to our community.

The Board will provide guidance and feedback which will be used by the Senior Team. It is imperative that your voice is heard, and listened to as we consider how we can best support the needs of the families we are here to support, so that we can align and balance these with our organisational objectives and direction of travel, to best support families across the UK impacted by Dravet Syndrome.

As well as informing DSUK's work, our Lived Experience Board connects families and carers affected by Dravet Syndrome with researchers. Members are invited to take part in Patient and Public Involvement and Engagement (PPIE) activities that help shape how research and services are designed; this means working with researchers to improve studies, rather than simply participating in them. PPIE activities may be organised by DSUK, universities, pharmaceutical companies, or market research organisations.

Researchers designing studies often don't understand what it's really like to live with Dravet Syndrome. Your perspective helps develop research that's genuinely useful and achievable for families like yours.

What you will do as a Board Member

Board members may be invited to participate in various activities, all of which are voluntary.

As a member of the Board, you will be invited to share your perspectives and experiences to help inform DSUK's work. Activities may include:

- Attending Board meetings
- Sharing feedback on current or proposed family services
- Contributing ideas for new areas of support – please be aware not all ideas will be able to be actioned but will help shape service development.
- Reflecting on the needs and priorities of families affected by Dravet Syndrome
- Reviewing materials, communications, or resources where appropriate

For scientific research, members work with researchers to improve study design before research begins, and sometimes whilst it is ongoing. Activities might include:

- Surveys and polls
- Group discussions and workshops
- Providing feedback on study protocols
- Reviewing patient information documents and plain language summaries
- Meeting with researchers to share your experience of Dravet Syndrome

Board members may also be interested in research participation including surveys, interviews, and other activities. DSUK will share research participation opportunities with the board, but this is always optional and separate from PPIE advisory work.

How Opportunities are Shared

Family Services Opportunities

1. We will share the meetings that are coming up, alongside an agenda typically via a quarterly email update. We will provide clear information about each meeting, agenda and time commitment, and where required whether reimbursement is available, and who is running it.
2. You can choose which opportunities you would like to take part in, and you are never obliged to say yes. You will be asked to respond to the quarterly email to let us know if you can attend any of the proposed meetings.
3. We will then email to confirm your attendance.

Scientific Opportunities

1. When researchers contact DSUK asking for PPIE, DSUK will assess whether the project is beneficial to the community and appropriate for the board. DSUK retains discretion over which opportunities are shared.
2. If approved, we will share the opportunity with board members, typically via a monthly email update. We will provide clear information about each activity before you are asked to take part, including information about the project, the time commitment, whether reimbursement is available, and who is running it.
3. You can choose which opportunities you would like to take part in, and you are never obliged to say yes. You will be asked to respond to the monthly email to let us know which (if any) projects you would be willing to participate in.
4. DSUK will collect responses and share the contact details of interested members with the researcher, who will then contact you directly about the project.

If More People Volunteer than Needed

If more people volunteer than are needed for a particular activity, DSUK will try to share opportunities fairly. We will aim to include a mix of experiences and consider how many activities someone has done recently, so no one is over-burdened. If you volunteer for an activity and are not selected on that occasion, this is never a reflection on you or your experience. We will continue to offer other opportunities in the future.

Time Commitment and Membership

The Board will meet quarterly.

- The initial meeting will be held in person
- Subsequent meetings will be predominantly online

DSUK will lead and facilitate all meetings. Meetings will be structured, with clear agendas and opportunities for discussion.

For scientific activities, typical involvement is around three to six activities per year, with each activity usually taking one to two hours. This is deliberately manageable to respect your time and other commitments. You will never be pressured to take part in any specific activity.

There may occasionally be a small requirement for feedback via email, or an exceptional request for an additional meeting where necessary. We will provide materials in advance wherever possible. We recognise the demands on families and aim to keep involvement manageable and respectful of your time

When joining the board, you are not committed to stay on for a set period. You can leave at any time by notifying DSUK, and you may request a pause in your involvement (for example, during a crisis or period of high care demands).

To ensure diverse representation across demographics and maintain sustainable board size, applications may be paused when at capacity or placed on a waiting list.

At the end of each year, we will check in with members to identify those who are active and want to continue, whilst deliberately bringing in new members to maintain freshness and broaden representation. We will continuously monitor engagement and activities. If we identify that a member may be taking on too much, we will discuss this with them and adjust their involvement accordingly.

Reimbursement and Recognition

DSUK advocates for researchers to reimburse board members for their time and expertise, but reimbursement depends on the organisation running the activity. We will always let you know in advance whether reimbursement is available for any specific activity.

DSUK is committed to showing you how your involvement makes a difference. When researchers complete PPIE activities with the scientific research board, we will ask them to provide a summary of how your input was used and what changed as a result. We will share these summaries with you so you can see the real-world impact of your contributions.

We advocate for researchers to publicly acknowledge the input from DSUK's Lived Experience Board where appropriate, ensuring that your contribution to improving research is recognised.

How DSUK Supports You

DSUK will provide ongoing support throughout your time on the board. If you need assistance understanding materials, have questions about activities, or require any accommodations to participate fully, please contact us. DSUK will join group activities to ensure a safe, structured, and accessible environment.

DSUK will liaise with researchers before, during, and after PPIE activities. We ask researchers to keep DSUK copied on all communications with board members, so that we can monitor workload and keep track of progress. We also ask that researchers only contact you regarding the agreed activity, and to liaise with DSUK about additional updates and future work, so that you are not over-burdened.

We take all feedback seriously and will investigate any concerns about safeguarding, discrimination, or breach of confidentiality. We also welcome your feedback on how the board is working. If you have suggestions for improvement, concerns about any activities, or ideas for how we could better support board members, please let us know.

Confidentiality

As a board member, you may hear confidential or sensitive information about research in development, or unpublished data. We ask that you do not share details outside the group unless given explicit permission. You may be asked to sign a confidentiality agreement before certain activities. If you are unsure if information is confidential, please check with DSUK.

Whilst you retain ownership of your personal experiences and stories, insights generated through PPIE activities may be used by researchers in their work.

DSUK will keep your contact information and feedback secure in accordance with data protection regulations (UK GDPR); we won't share your details with external researchers or partners without asking you first. If you leave the board, we will remove you from future communications. We keep records of your participation for evaluation purposes only.

Please be assured that any information you share about your personal experiences will be treated confidentially within the group. However, there may be rare occasions where something you share raises concerns beyond the context of your family's needs. In such cases, we may discuss this with you as part of our safeguarding responsibility. This is to ensure that you receive the appropriate support and that everyone remains safe.

Conflicts of Interest

If you have a relationship or interest that could be perceived as a conflict of interest you must declare this as soon as you become aware of it. Examples may include, but are not limited to:

- Family relationship or close personal relationship with the researchers.
- Financial interest in the project or organisation.
- Professional collaboration with the researcher

There's no judgement, we just manage it transparently so no one questions the fairness of decisions. DSUK may ask you not to join that specific project to avoid conflicts of interest. This protects both you and the integrity of the PPIE process.

Reviewing This Document

This handbook may be updated based on board members' experiences and feedback, or changes in best practice. We will inform you of any significant changes and give you the opportunity to discuss them. The current version will always be available, and you can request a copy at any time.

Questions?

If you have any questions about being a board member or would like to discuss anything in this document, please contact us at familyexperience@dravet.org.uk.