DRAVET Syndrome UK

Hope for families with life-limiting epilepsy



Dravet Syndrome UK

Research Strategy 2026

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1. Introduction

Dravet Syndrome UK is a charity dedicated to bringing hope to families living with Dravet Syndrome through support, education and medical research. We are an independent charity and the only UK organisation dedicated to improving the lives of those affected by Dravet Syndrome.

This research strategy outlines how Dravet Syndrome UK will fund research over the period 2027–2032 with a vision of:

Catalysing high-quality research that leads to better understanding, management and outcomes for people living with Dravet Syndrome across the lifespan.

Ensuring that research funded by Dravet Syndrome UK addresses the questions and unmet needs that matter most to people living with Dravet Syndrome, and generates evidence that improves decision-making and access to care.

Strengthening the Dravet Syndrome research landscape in the UK, in close connection with international programmes and collaborations.



2. Our funding approach

Dravet Syndrome UK will support research that is scientifically and ethically sound, and clearly relevant to our priority areas. We are particularly interested in studies that are shaped by lived experience, include meaningful involvement, and have the potential to directly improve understanding, management, care or outcomes for people with Dravet Syndrome.

Grant calls will be issued on a biennial basis and will set out detailed information on funding processes, assessment criteria and application requirements. Alongside grant calls focused on our priority themes, Dravet Syndrome UK will remain open to enabling studies that support progress in Dravet Syndrome research, even where they do not fit neatly within a single category, provided their benefit to the community is clear.

All proposals will be assessed using reviews from both scientific experts and Experts by Experience.









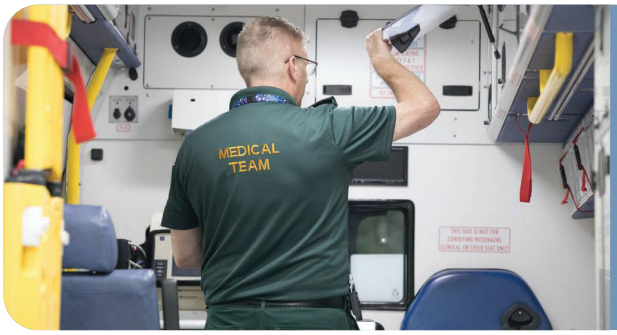
3. Priority areas

Dravet Syndrome UK's five-year strategy for 2021-2026 set out our aim to deliver ongoing and new research that puts the needs of the families living with Dravet Syndrome at its heart. Building on this, the research priorities for 2027–2032 reflect areas where families have identified important unmet needs and where Dravet Syndrome UK believes targeted funding can make a meaningful difference.

Our priorities for 2027-2032 are:



1 **Behaviour that challenges, mental health and emotional wellbeing**



2 **Coordinating care across the system**



3 **Impact on parents, siblings and the wider family**



4 **Home, care and planning ahead**



5 **Thinking, learning and communication**



6 **Movement, balance and physical ability**

Each grant call will set out specific sub-themes under every priority area to highlight the topics we are particularly interested in funding. We recognise that evidence on Dravet Syndrome in adulthood is currently more limited, and to address this, every priority area will include at least one adult-specific sub-theme within our grant calls.



3a. How priorities were developed

In 2025–2026, Dravet Syndrome UK ran a priority-setting project inviting families to share the areas they most wanted researched, then ranked these with the community to identify shared priorities. The results of this project have directly informed our priority areas.



4. Scope of Dravet Syndrome UK research funding

Dravet Syndrome UK will support a broad range of research relevant to Dravet Syndrome, including but not limited to:



Mechanistic and biological research

Improving understanding of the causes and physiology of Dravet Syndrome through human studies.



Intervention research

Developing and evaluating intervention protocols and supportive approaches, including behavioural, communication or physical approaches, and appropriate outcome measures.



Health and social care services research

Using service evaluation, implementation science or health economics methods to understand what improves the organisation, coordination and delivery of care.



Qualitative and psychosocial research

Using interviews, surveys or other qualitative methods to understand experiences, needs and what works in practice.



Longitudinal and data-driven research

Using cohort or long-term data to identify trends, patterns or changes in needs, care and outcomes over time.

Dravet Syndrome UK will primarily fund public and not-for-profit research organisations in the UK, and welcome applications from researchers at all career stages. Detailed eligibility requirements are set out in individual grant calls.

5. Involvement, equity and inclusion

5a. Patient and public involvement and engagement (PPIE)

Involvement and engagement of people with Dravet Syndrome and their families is central to this strategy. Dravet Syndrome UK will:

- Involve people with lived experience in setting research priorities, shaping grant calls and participating in appropriate review and decision-making processes.
- Require applicants to describe PPIE activities that shaped the proposal and will be implemented throughout the project.
- Provide guidance and support to researchers on high-quality and inclusive PPIE.

Dravet Syndrome UK expects involvement to be meaningful and proportionate to the nature of the study, and to improve the relevance, design, conduct and dissemination of the research. To support this, Dravet Syndrome UK's Lived Experience Board will be available to provide Dravet Syndrome UK-funded projects with co-design and review of materials and protocols.

5b. Equity, diversity and inclusion

Dravet Syndrome UK recognises that people with Dravet Syndrome and their families are diverse, and that research must reflect this diversity in its questions, methods, and teams.

Applicants will be expected to consider:

- Study designs that support inclusion across the lifespan (where appropriate), across the full severity spectrum, and among minority ethnic and lower socio-economic groups.
- Diversity within PPIE activities and advisory structures, so that a range of lived experiences can shape the work.

Over time, Dravet Syndrome UK will also review which researchers and institutions it supports and, where gaps are identified, use targeted funding to improve representation.

6. Partnerships and collaboration

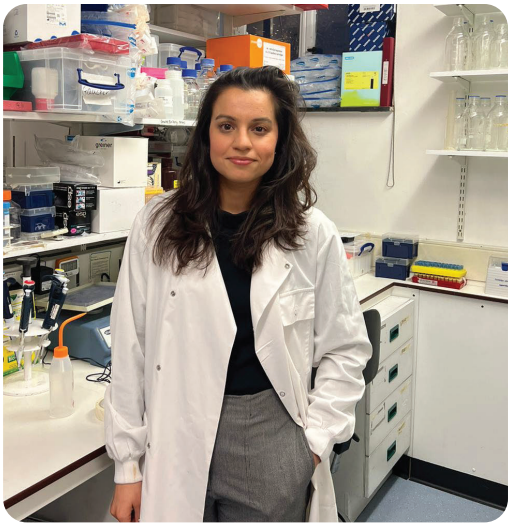
To increase impact and make best use of resources, Dravet Syndrome UK is open to collaboration with:

- Other Dravet Syndrome and rare-epilepsy charities in the UK and internationally.
- Broader organisations, research institutes and NHS organisations.
- Public or charitable funders of health research.

Collaborations may involve co-funding projects, shared infrastructure or joint calls. Any such collaboration will be guided by clear agreements and will respect Dravet Syndrome UK's independence in setting priorities and making funding decisions.









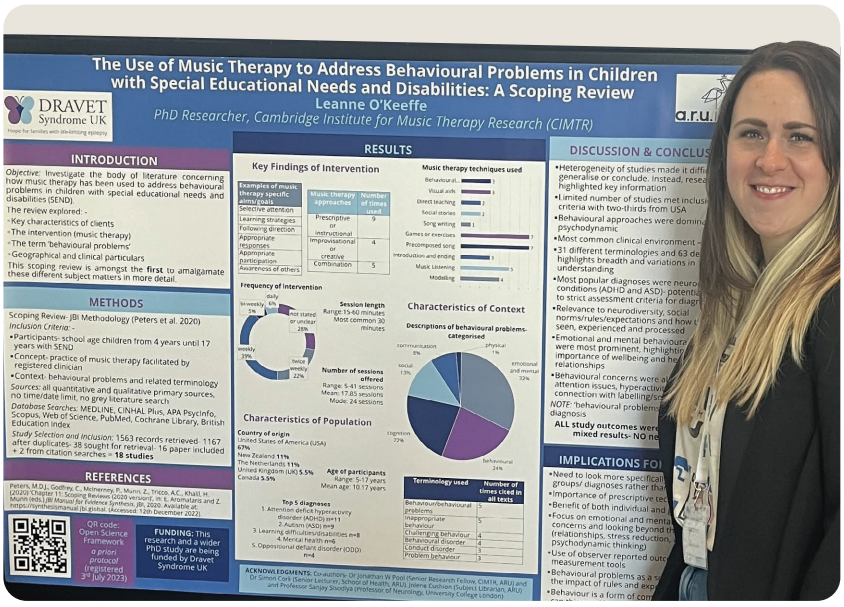
7. Measuring impact and reviewing the strategy

Dravet Syndrome UK is committed to understanding and maximising the impact of its research funding. Dravet Syndrome UK recognises that, particularly in rare disease research, impact may emerge over different timescales and in different forms.

Over the lifetime of this strategy, Dravet Syndrome UK will:

- Track outputs such as publications, conference presentations, tools and datasets from funded projects to record the breadth of impact and awareness.
- Seek evidence of changes in clinical practice, services or policies as a result of Dravet Syndrome UK-funded research.
- Review the extent to which funded projects and their outcomes address priority areas.
- Synthesise and share key learning and impact stories with stakeholders.

This strategy will be reviewed after each grant round to identify unactioned priorities and inform adjustments to future calls, and more comprehensively every five years to ensure alignment with best practice and the evolving research and funding landscape.







DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

Dedicated to improving the lives of people affected by Dravet Syndrome through support, education and research

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