

Dravet Syndrome UK 

Strategy

2021 to 2026



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About Us

Dravet Syndrome

Dravet Syndrome is a rare, life-long and life-limiting neurological condition, affecting one in every 15,000 people in the UK. As well as severe, difficult-to-control seizures, Dravet Syndrome encompasses intellectual disability and a spectrum of associated conditions (known as 'comorbidities'), which may include autism, ADHD, behaviours that challenge and difficulties with speech, mobility, feeding and sleep. Every child or adult with Dravet Syndrome is different, with some affected more severely than others, or with a different emphasis across symptoms and comorbidities. But for all, the condition is complex and can be highly unpredictable.

Dravet Syndrome UK

Dravet Syndrome UK (DSUK) was created in 2008 by a group of parents who came together looking for support, resources and information relating to Dravet Syndrome. Today, our database has grown to over 500 families across the UK. We are an independent charity and the only UK organisation dedicated to improving the lives of those affected by Dravet Syndrome.

Mission

To bring hope to UK families living with Dravet Syndrome through support, education and medical research.

Aims

1. **Support:** To support families affected by Dravet Syndrome emotionally, practically and financially.
2. **Education:** To raise awareness and understanding of Dravet Syndrome among medical professionals
3. **Research:** To fund medical research to increase understanding of Dravet Syndrome, improve its management, work towards better outcomes and hopefully one day find a cure.

Welcome

I'm really pleased to be introducing DSUK's first strategy.

This strategy marks an important milestone in our charity's journey. From a group of 30 families who came together looking for mutual support in 2008, to a registered charity helping over 500 families with support, education and research services underpinned by a world class medical advisory board we have come a long way. Now we are looking ahead to the next stage in our development.

As a parent of a 13-year-old boy with Dravet Syndrome, I know first hand the difference DSUK's support can make to the lives of families living with this devastating condition and the importance of being able to connect with other families, apply for grants, access the latest information, know that clinicians are part of the conversation and that vital research is being undertaken.

We have come a long way supporting children and adults with Dravet Syndrome but there is further to go. Families are still waiting too long for a diagnosis. We do not know enough about the comorbidities of Dravet Syndrome and the spectrum nature of the condition. Transition into adult health care services remains challenging and many families struggle to access the statutory support they are entitled to.

Building on all we have achieved to date DSUK is setting out an ambitious five year strategy to shape what we do and the way we do it.

We want to reach more families, to deliver research that puts family needs first, to improve awareness and understanding amongst professionals, particularly in adult neurology and social services, and to give families the tools and support needed to assert their rights.

We know we have given ourselves a lot to do but we believe this is the right time to move forward and, more importantly, this is the right way for us to support everyone who have to live with Dravet Syndrome and all its challenges.

To deliver this strategy we will be putting robust plans in place, particularly to secure the resources needed to achieve our ambitions while also being responsive to the uncertainties of these times. With our families behind us and a strong and committed team of staff, trustees and medical advisors we are ready and excited to get on with this work.

There is so much to be hopeful for as we look ahead to 2026 and beyond - for 2026 is just the next milestone, not the end of the road. We are really excited by the possibilities of the coming years. There are gene therapies on the horizon, and other new treatments in development, as well as all the work we are planning with this new strategy. Today I look forward with confidence, excitement and hope that together we can and will make a difference for every family living with Dravet Syndrome in the UK.

G. Wilson

Galia Wilson
Chair of Trustees



Strategic Objectives

1. Every family matters

Every UK family living with Dravet Syndrome will be aware of DSUK and the support available, be enabled to access this support as required, and know that all activities and research are driven by the things that matter most to them.

2. Leaders in the field

DSUK will lead the conversation about Dravet Syndrome in the UK, making the best possible use of its research funds, collaborating internationally as opportunities arise, and developing an authoritative global voice.

3. Support for professionals

We will seek to broaden the range of health and social care professionals with an improved understanding of Dravet Syndrome, enabling earlier diagnosis and providing accessible pathways to the best possible treatment and care for all ages.

4. Empowerment of families

Families living with Dravet Syndrome will know and understand their rights and feel empowered to assert these rights to get the support they need.



1. Every family matters

Every UK family living with Dravet Syndrome will be aware of DSUK and the support available, be enabled to access this support as required, and know that all activities and research are driven by the things that matter most to them.

The focus of the first three years will be the expansion of DSUK's geographic reach, to ensure that every household and individual living with Dravet Syndrome in the UK has the opportunity to understand who we are and what we can offer them.

Recognising that families come in all shapes and sizes, we will commit during this period to ensure that we include people living with Dravet Syndrome from all social and demographic backgrounds in our work and with different experiences of living with Dravet Syndrome.

DSUK is dedicated to supporting people of all ages with Dravet Syndrome, from infants to older adults, and will develop new ways to reach and support adults specifically, ensuring parity of support with the offer for children and young people with Dravet Syndrome.

We are committed to involving families in the design and delivery of our work. We will conduct a comprehensive survey of needs at the outset of the period, from which we will identify opportunities to increase their involvement, ensuring their understanding and experience is at the heart of our support offer.

In the latter part of the period we will focus on enhancing the support we offer to DSUK families. As we do this, we will check in regularly with our growing community, as well as with families who are not registered with DSUK, to ensure that we continue to serve families in all our activities.

In meeting this objective, we aim not only to increase the number of families we serve but also to ensure that everyone living with Dravet Syndrome benefits from these services whatever their age, location, demography or social background.

Outcomes

- The DSUK community will be reflective of UK society, with no family left behind because of location, ethnicity or other reason.
- Families living with Dravet Syndrome will have the knowledge and support needed to ensure the best possible care for people with Dravet Syndrome.
- DSUK's services are tailored to meet the needs of families living with Dravet Syndrome.
- Health & social care professionals will refer families living with Dravet Syndrome to DSUK as the first port of call.

Measures of success

- Number of families registered with DSUK will grow by 70%.
- Take-up levels for DSUK's support services will grow by 80%.
- Make-up of DSUK families and take-up of DSUK services reflective of UK demographics.
- At least 80% recognise DSUK's name when surveyed in clinics.
- At least 95% of registered DSUK families surveyed agree that DSUK's support is "very good" or "good".



2. Leaders in the field

DSUK will lead the conversation about Dravet Syndrome in the UK, making the best possible use of its research funds, collaborating internationally as opportunities arise, and developing an authoritative global voice.

Our mission to give hope to families and people living with Dravet Syndrome demands that we assert ourselves as a leading voice in the health and social care sectors. We will seek to lead the conversation about holistic approaches to the care of people of all ages living with Dravet Syndrome and to represent everyone in Dravet Syndrome community equally and fairly.

At an exciting time in the development of new treatments for Dravet Syndrome, we will provide strong representation among clinicians and researchers, ensuring the needs of families living with Dravet Syndrome are at the heart of the design and delivery of ongoing and new projects.

In our own research work we will fund work in areas which have not been considered priorities but which are vital to families, such as associated conditions and comorbidities, non-clinical and cross-disciplinary research, to support people living with Dravet Syndrome to the fullest.

DSUK will always seek to promote the interests and rights of families at a national level and to promote recognition of Dravet Syndrome and equity of treatment across the UK. We will continue to advocate on behalf of families living with Dravet Syndrome through representation in associated patient groups. We will also plan and deliver a collaborative programme of activity with other UK rare disease and neurological charities.

As one of the leading Dravet Syndrome charities in the world, DSUK will continue to collaborate internationally, to ensure that the people we represent are equally represented when collective, co-ordinated action across national borders may be the most effective way to transform lives at home.

Outcomes

- New research projects, including DSUK funded projects, will meet the needs of families living with Dravet Syndrome, as their voices will be heard through treatment development.
- Dravet Syndrome will be recognised as a life-long condition affecting both adults and children, with as much emphasis given to improving treatments for adults as there is for children.
- Professionals working in the field of Dravet Syndrome will look too DSUK as a first-choice partner for thought leadership, and make the best possible use of research findings, including those funded by DSUK.

Measures of success

- At least 80% of DSUK families say new research projects have been developed with consideration to their needs.
- At least 60% of DSUK families will report improved clinical management of Dravet Syndrome comorbidities and quality of life for the person living with Dravet Syndrome and the wider family.
- At least 80% of professionals working on Dravet Syndrome surveyed will say DSUK is a key partner in their work.



3. Support for professionals

We will seek to broaden the range of health and social care professionals with an improved understanding of Dravet Syndrome, enabling earlier diagnosis and providing accessible pathways to the best possible treatment and care for all ages.

Our engagement with the wide range of health and social care professionals who work so hard to support families living with Dravet Syndrome will be a renewed priority for us in the next five years, starting with a comprehensive review of the current relationships to identify areas for development. We will also conduct a review of the role and membership of the DSUK Medical Advisory Board.

Targeted campaigns over the period will seek to inform and engage adult neurologists, multi-disciplinary teams and the next generation of doctors amongst other groups in the diagnosis and management of Dravet Syndrome. We will explore partnership working to improve the impact of the campaigns we run and to ensure we use DSUK resources efficiently.

We propose a new focus on social care, where we recognise a historic lack of support and education. A programme to identify and engage social care professionals will seek to bridge the information gap which is widely perceived currently.

In addition to tracking innovation in health and social care research and practice, we will continue to promote learning from the research that we fund (including the natural histories project) and to build relationships with research partners which will support health and social care professionals in their work.

Building on the success of our past conferences, we will undertake a review to determine the best ways in which we can make the most of new technologies to deliver collegiate engagement and educational opportunities for as many of our professional colleagues as possible in a changing, challenging world.

Outcomes

- The health/social care community will have a better understanding of Dravet Syndrome and be better equipped to manage the condition.
- People with Dravet Syndrome will be diagnosed earlier and started on the best course of treatment sooner, improving their outcomes.
- There will be equity in care for people with Dravet Syndrome irrespective of age, improving longer term outcomes.
- The management of co-morbidities will be given equal consideration to seizures, improving overall quality of life.

Measures of success

- The rate by which the average age for a Dravet Syndrome diagnosis in undiagnosed children drops (rate to be determined once baseline set).
- The rate by which the average age for a Dravet Syndrome diagnosis in previously undiagnosed or misdiagnosed adults increases as more receive a correct diagnosis.
- Health and social care satisfaction levels will be equitable for both families with children who have Dravet Syndrome and families with adults who have Dravet Syndrome.
- At least 60% of DSUK families will report improved clinical management of Dravet Syndrome comorbidities and quality of life for the person who has Dravet Syndrome & the wider family.



4. Empowerment of families

Families living with Dravet Syndrome will know and understand their rights and feel empowered to assert these rights to get the support they need.

We firmly believe that the most effective way in which we can support families is in empowering them to understand and assert their rights and in supporting them to navigate a path through what can be challenging worlds of health, education and social care.

We will engage with families to better understand the barriers they face to asserting their rights to get support. As an outcome of this we expect to develop a set of practical tools and materials to support their self-advocacy in interactions with a range of stakeholders, including healthcare providers, local and national government agencies, schools and educational institutions and child and adult care providers.

As the DSUK community grows, we will also seek to advocate on behalf of families both collectively and at an individual level.

Recognising that families living with Dravet Syndrome also engage with a wide range of other authorities and stakeholders, we will develop our own working practices with partner organisations to maximise the positive impact that we can have on behalf of our families.

Outcomes

- Parents/carers of people with Dravet Syndrome will feel more empowered to assert their rights when engaging with public services, improving access to these services particularly respite for parents/carers.
- DSUK families will experience less financial hardship because of Dravet Syndrome, through sign posting by DSUK to access grants, benefits, and other forms of financial support.
- DSUK support will mitigate the impact Dravet Syndrome can have on the well-being of DSUK families.
- DSUK will have all the resources required, available in an accessible format, to empower Dravet families.

Measures of success

- **At least 80% of DSUK families agree that:**
 - They feel more knowledgeable about their rights
 - They feel more confident and empowered to assert their rights
 - Their financial circumstances are less impacted by Dravet Syndrome
 - Their well-being is less impacted by Dravet Syndrome



**Bringing hope to UK
families living with
Dravet Syndrome through
support, education and
medical research.**



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