

JOB DESCRIPTION

CEO, Dravet Syndrome UK

Job Title	Chief Executive Officer
Reports to	Board of Trustees
Directly line manages	Head of Fundraising, Head of Family Services, Head of Marketing & Communications, Chief Scientific Officer
Location	Home-based, with regular travel across the UK and occasional international travel
Hours	Full-time, 40 hours per week
Working Pattern	Monday to Friday, 09:00–17:30 (some flexibility for evenings and weekends required)
Salary	£70,000
Annual Leave	24 days plus 8 bank holidays (full-time equivalent)
Pension	In line with statutory requirements
Contract Type	Permanent

About Dravet Syndrome

Dravet Syndrome is a rare, life-long and life-limiting form of epilepsy that affects approximately one in every 15,000 live births in the UK (we estimate there are between 2-4,000 people living with the condition). Everyone with Dravet Syndrome has complex, additional needs – it is more than epilepsy. As well as severe, treatment-resistant seizures, the condition encompasses intellectual disability and a spectrum of difficulties including with speech and language, mobility, behaviour, eating and sleep. A co-diagnosis of autism and/or ADHD is also common.

Dravet Syndrome carries a high risk of early death. The risk of SUDEP (Sudden Unexpected Death in Epilepsy) is up to 15 times higher than for other childhood-onset epilepsies, and sadly around 15–20% of children currently do not survive to adulthood.

Receiving a diagnosis of Dravet Syndrome is profoundly life-changing. The condition affects every area of life and impacts the whole family. While we are living in an increasingly hopeful time, with disease modifying (gene) therapies currently going into clinical trials (the first ever gene therapies to be developed in epilepsy), families affected by Dravet Syndrome continue to face many challenges.

About Dravet Syndrome UK

Dravet Syndrome UK (DSUK) is a registered charity dedicated to improving the lives of everyone affected by Dravet Syndrome through family support, professional education and medical research. Founded in 2008 by a group of parents, the charity has grown significantly over the past 17 years.

Today, DSUK supports nearly 600 registered families across the UK and reaches over 2,000 people in total, including parents and carers, siblings and bereaved families. Our work spans three interconnected areas:

- **Family support:** practical, emotional and financial help for families, including grants, an annual family weekend away, a private online community, regional meet-ups and a range of resources to help families navigate everyday life with Dravet Syndrome
- **Professional education:** raising awareness of Dravet Syndrome among healthcare professionals, social care, education and others involved in the care of those with the condition (e.g. via our website, social media, newsletters, attendance at national and international meetings). Our biennial conference is the only dedicated scientific meeting for Dravet Syndrome in the UK
- **Research:** funding and partnering on research focused on family-defined priorities, including the SCN1A Horizons Natural History Study across 29 NHS hospitals. In 2025, we appointed our first Chief Scientific Officer, funded by an \$800,000 international grant from the Chan Zuckerberg Initiative

In the past five years, DSUK has undergone a period of significant growth: income has increased from approximately £340,000 in 2022 to £630,000 in 2026, and our team has grown from four to nine staff. The charity has completed its first five-year strategy and is now planning its next chapter for 2026–2030.

Why This Role Matters Now

The charity has built solid foundations over the past five years. Now we are looking for an experienced CEO to lead us into our next phase. This is a scale-up role, rather than a start-up role.

We are seeking a leader who can inspire and develop a talented team, engage stakeholders, build strategic partnerships to drive further growth, and deliver our next 5-year strategy; all in the context of a dynamic and fast-changing external environment.

Purpose of the Role

The CEO is the most senior member of staff and is accountable to the Board of Trustees for the overall leadership, performance and strategic direction of the charity. You will work in close partnership with the Board to shape and deliver the next five-year strategy, and you will lead a team of nine, with four direct reports across fundraising, family services, marketing and communications, and scientific leadership.

This is a varied and hands-on role that requires you to operate confidently at both a strategic and operational level. On any given day, you might be preparing a board report, building a relationship with a clinical partner, supporting a member of the team through a complex challenge, representing the charity at a conference or thinking through their positioning in the rare disease landscape.

Because the charity does not have an in-house HR or Finance function, the CEO carries those responsibilities directly, supported by external advisors. It is a fully remote organisation, so the successful candidate will also need to be experienced and confident in leading a dispersed team.

Key Responsibilities

1. Leadership and People Management

- Provide strong and visible leadership to the whole organisation; ensuring clarity of purpose and creating a culture where people feel supported and motivated to do their best work

- Line manage the Head of Fundraising, Head of Family Services, Head of Marketing & Communications, and Chief Scientific Officer; support each to lead their areas with confidence and to develop as leaders in their own right
- Lead on all HR matters including recruitment, induction, performance management, appraisals and any wellbeing or disciplinary issues, drawing on external HR support as needed
- Ensure strong communication and collaboration across a fully remote team, with particular attention to how the team works together across functions
- Champion a culture of openness, inclusion, continuous learning and shared accountability

2. Strategy and Planning

- Lead the development of 2026–2030 strategy with the Board of Trustees, ensuring it is grounded in the needs of families, responsive to the changing rare disease landscape, and realistic about what the organisation can deliver
- Oversee delivery of the strategy across all areas of the charity's work, setting clear priorities and success measures and keeping the team focused on what matters most
- Regularly review progress against strategic goals, identify risks and emerging opportunities, and bring well-reasoned recommendations to the Board
- Stay closely informed about developments in the wider sector (scientific advances, policy changes, funding trends, the work of other patient organisations) and ensure the charity remains well-positioned

3. Stakeholder Relationships and External Profile

- Represent the organisation externally with credibility, warmth and authority – at clinical conferences, in the media, with funder and partner organisations, and within the rare disease and patient advocacy community
- Build and sustain a network of high-value relationships across the clinical, scientific and pharmaceutical sectors that advance the mission and open up new opportunities for collaboration and funding
- Develop strong, productive relationships with key healthcare professionals, researchers and institutions, ensuring the organisation is regarded as an essential partner in the UK landscape
- Represent the voice of families in across the organisation's external work, ensuring it remains genuinely driven by the needs and priorities of the people it serves
- Navigate the charity's positioning within the wider rare epilepsy and patient organisation community with strategic care

4. Income Generation and Financial Sustainability

- Provide strategic oversight of fundraising activity, working closely with the Head of Fundraising to set direction, agree ambitious but realistic targets and ensure the charity has the right income mix for long-term sustainability
- Ensure the fundraising strategy is well-resourced, properly evaluated and integrated with the charity's broader communications and partnerships work
- Build and maintain relationships with a small number of high-value funders and major donors where personal CEO-level engagement is appropriate and strategically important
- Ensure the charity has a compelling narrative about its impact that resonates with different funder audiences – from grant-makers to corporate partners to individual supporters

Income context: organisational income has grown from £340k to £630k over five years. The current mix is: grants 49% (including a £150k/year CZI capacity-building grant running to 2030), community fundraising 43% and corporate 6%. Community fundraising needs recovery. Major donor and corporate income are priorities for the next strategy period.

5. Financial Management

- Take overall responsibility for the charity's financial health, working with the Board treasurer and external accountants
- Set and manage the annual budget, monitoring performance throughout the year and taking corrective action where needed
- Oversee the production of management accounts, statutory accounts and the annual report
- Ensure appropriate financial controls are in place and regularly reviewed, and that the charity maintains adequate reserves
- Identify financial risks early and take prompt, well-judged action to address them

6. Governance and Compliance

- Work closely with the Board of Trustees to ensure governance arrangements remain appropriate, effective and up to date
- Attend quarterly board meetings and prepare clear, timely reports on performance, risks and decisions required
- Ensure all policies and procedures (including safeguarding, data protection, health & safety and equality & diversity) are in place, understood and followed
- Ensure the charity remains compliant with Charity Commission requirements and all relevant legislation, including robust DBS and safeguarding arrangements
- Maintain and regularly review the charity's Risk Register

7. Operations

- Take overall responsibility for the effective delivery of charitable activities across support, education and research, ensuring alignment to the strategic plan
- Provide oversight for in-house support functions/infrastructure including administration, finance (banking) and shared digital systems (including the CRM and website), drawing on support from suppliers where relevant
- Ensure robust monitoring, evaluation and learning is embedded across the charity's work
- Commission and manage external suppliers, advisors and contractors as required

Person Specification

The table below sets out what we're looking for in our next CEO. We know that not everyone will have every item - if you have most of the essentials and are genuinely excited about this role, we'd love to hear from you.

What we're looking for	Essential	Desirable
Experience		
Proven track record as a CEO, CEO or equivalent senior leader in the charity or not-for-profit sector	✓	
Experience of leading an organisation through growth - whether of income, team size or programmes - and managing the complexity that comes with it	✓	
Demonstrable success in building, motivating and developing high-performing teams, ideally in a small or remote-working organisation	✓	

Experience of working effectively with a board of trustees, including reporting, governance and strategic partnership	✓	
Experience of financial management and oversight, including budget setting, management accounts and reporting to a board	✓	
Experience of building and managing a wide range of external stakeholder relationships - including funders, clinical or professional communities, partner organisations and the media	✓	
Experience of overseeing income generation and fundraising at a strategic level - setting direction, supporting a fundraising team and understanding what drives success across different income streams		✓
Experience working in a health, disability or patient advocacy charity - ideally at national level		✓
Skills and Knowledge		
Outstanding leadership and people management skills - a natural motivator who creates environments where people do their best work	✓	
Excellent communicator and relationship-builder - equally confident in the boardroom, at a clinical conference, with a family affected by Dravet Syndrome or in the media	✓	
Strategic thinker with the ability to translate vision into clear priorities and tangible plans, and to keep a team focused on what matters most	✓	
Strong financial literacy - able to interpret accounts, manage budgets and present financial information clearly to non-finance audiences	✓	
A good understanding of income generation and what makes fundraising strategies succeed - sufficient to provide confident strategic direction to a fundraising team	✓	
Understanding of good governance, charity law and regulatory compliance	✓	
Understanding of HR principles and employment law (the charity does not have an in-house HR function)		✓
Knowledge of the rare disease, epilepsy or neurology landscape - including the clinical, research and patient organisation communities		✓
Personal Qualities		
Genuine passion for DSUK's mission and a deep commitment to the people the charity serves	✓	

Resilient and adaptable - comfortable with the breadth and pace of a small charity CEO role, and able to hold the big picture and the day-to-day detail at the same time	✓	
Credible and confident external ambassador - comfortable representing DSUK at senior levels across the health, research and voluntary sectors	✓	

Additional Information

DSUK is committed to equality of opportunity and welcomes applications from all sections of the community. We are a small, remote-working team and value flexibility, trust and a genuine commitment to our mission above all else.

The role involves travel approximately every four to six weeks across the UK to attend events, meetings and conferences. Occasional international travel may be required. Some out-of-hours working is expected - particularly around our annual family weekend, conference and key fundraising events - with time off in lieu provided.

The successful candidate will be subject to a Disclosure and Barring Service (DBS) check.

Dravet Syndrome UK | Registered Charity No. 1132253 | www.dravetsyndromeuk.org