



# DRAVET Syndrome UK

Hope for families with life-limiting epilepsy



Head of Fundraising

Candidate Information Pack

January 2024

*'DSUK has made a huge difference to people living with Dravet Syndrome. It has raised awareness of Dravet Syndrome, represented people affected by Dravet Syndrome, has been a source of support to which I can refer families, and has raised funds for, and funded, much research into the condition.'*

Professor Sanjay Sisodiya, Professor of Neurology at UCL Institute of Neurology



## About us

Dravet Syndrome is a rare life-limiting neurological condition, occurring in around 1 in 15,000 live births. It's often described as a form of epilepsy; however, epilepsy is just one aspect of Dravet Syndrome. As well as severe, difficult-to-control seizures, children and adults with Dravet Syndrome have varying degrees of learning disability and a spectrum of associated conditions – known as comorbidities. These can include autism, ADHD, challenging behaviour and difficulties with speech, mobility, eating and sleep disorders. Dravet Syndrome is a devastating condition that has a huge impact on individuals, caregivers and their families.

Dravet Syndrome UK (DSUK) is a small, independent charity dedicated to improving the lives of those affected by Dravet Syndrome through support, education and research. The charity was founded in January 2009 by a small group of 30 families. Today, there are over 500 families registered with us and we have gained international respect and recognition for our work to bring hope to families affected by this catastrophic condition. We are also privileged to work with a world-class [Medical Advisory Board](#), whose guidance helps inform our activities. In 2021, we launched our [first five-year strategy](#) - a roadmap to guide our mission and enable us to reach more families, educate more professionals and fund more research.



# A message from the Chair

We're excited to be recruiting for a Head of Fundraising to join Dravet Syndrome UK. We have created this new senior role to help drive the charity forward at a pivotal stage in our development.

Families are at the heart of everything we do at Dravet Syndrome UK. As a parent of a 15-year-old boy with Dravet Syndrome, I know first-hand the difference that the charity'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.

In recent years, there have been exciting developments in the medical and scientific environment surrounding Dravet Syndrome. With advances in genetic research, there are new gene therapies on the horizon and other treatments in development, there's more interest in Dravet Syndrome than ever before, with untapped opportunities for our small charity to diversify and grow.

To enable us to achieve our long-term strategic goals, we are looking to recruit a skilled and passionate fundraiser, with the experience and drive to increase the impact of our work, by helping us to reach beyond our existing audience, diversify income and to build a sustainable financial model.

We're really looking forward to growing our team with this significant new appointment. Together I know we can make a real and lasting difference for every family living with Dravet Syndrome in the UK.

[Eastside People](#) is managing the recruitment process on our behalf and they will be delighted to discuss this opportunity with you.

We look forward to receiving your application.

**Galia Wilson, Chair of Trustees**

# Head of Fundraising

<b>Salary</b>	£45,000 to £55,000 per annum pro rata
<b>Location</b>	Remote, with a requirement to travel to national meetings (approx. six times a year)
<b>Contract Type</b>	Permanent, open-ended
<b>Hours</b>	24 hours per week (0.6 FTE)
<b>Reports to</b>	Director
<b>Benefits</b>	24 days annual leave plus 8 Bank Holidays per annum FTE. Pension in keeping with statutory requirements.

As part of **our commitment to safeguarding**, the postholder is expected to undertake an enhanced DBS check.

## Job Purpose

Head of Fundraising is a newly created senior role to enable DSUK to drive forward with the implementation of our five-year strategic plan. This is an exciting opportunity to join a growing organisation and help guide the next stage of our development, enabling us to make a positive difference in the lives of more people affected by Dravet Syndrome in the UK.

We're looking for a passionate, skilled, hands-on and collaborative colleague with significant experience in fundraising for non-profit organisations. You will need a proven track record of developing and implementing fundraising strategies and activities across a range of fundraising income streams including trusts and foundations, individual giving and major donors, community, corporate and events.

As a senior fundraiser in a small charity, you will drive the development and implementation of a fundraising programme to grow and diversify DSUK's income, with a focus on developing new and sustainable channels of income. There are no current line management responsibilities, but you will be expected to work closely with and support the development of other team members involved in the charity's fundraising efforts.

## About the Team

Close teamwork is essential at DSUK. Our small team is home-based (no central office) but remains closely connected throughout the working day, utilising remote working technology.

The Head of Fundraising is both a strategic and an operational role. As part of the senior team, you will actively contribute to the strategic direction, planning and leadership of DSUK. You will show an aptitude for teamwork and collaboration and will work closely with the Director and the Marketing, Communications and Fundraising Manager. You will know about safeguarding and understand the importance of embedding an open, honest, and transparent culture.

## Key Responsibilities

### Strategic Planning

---

- Develop, implement and optimise a forward-looking fundraising strategy, ensuring we achieve our ambitious fundraising targets by multiplying restricted and unrestricted income over the next five years
- Report to the Director and the Board of Trustees routinely and ad hoc as required on strategy, progress against targets and forward planning
- Work with staff team and Trustees to develop fundraising plans to maximise impact and results

### Fundraising

---

- Seek out and develop new opportunities for long-term, mutually beneficial partnerships with new major donors and/or corporates/organisations, achieving multi-year gifts or contracts (please note legacy fundraising is not currently a strategic priority)
- Work with Marketing, Communications and Fundraising Manager to build and maintain a pipeline of funding opportunities from Trusts and Foundations, with a long-term focus on building sustainable relationships to secure larger grants; prepare and submit high-quality and tailored proposals/applications for support
- Support the highest standards in donor relations and supporter care, ensuring the highest levels of stewardship

- Optimise the charity's approach to community fundraising, including maintaining and developing an inspiring programme of individual/collective events, appeals and campaigns focused on unrestricted fundraising
- Work with colleagues across the charity to provide communications around fundraising efforts that resonate with key audiences
- Implement relevant processes, systems and policies to maximise fundraising success, including utilising the charity's technological resources to enhance donor relations and encourage best practice engagement
- Support the governance of fundraising which meets the needs of the organisation and sits within legal and best practice frameworks, including the Fundraising Regulator
- Monitor the impact of income generating activities, analysing as required to enable informed decision-making about income priorities going forward

## Teamworking

---

- Lead and support the fundraising function within DSUK and be a source of expertise, knowledge, support and guidance for colleagues, instilling a culture of professionalism and inclusion.

## Professional Engagement

---

- Represent DSUK at appropriate external meetings, as requested by the Director (you may sometimes be asked to work outside office hours and to undertake national travel; time off in lieu will be provided.)
- Support and promote diversity and equality of opportunity in the workplace for both staff and volunteers.

# Person specification

## Experience, Skills and Knowledge

---

### Essential

- Demonstrable experience of working in a small team, with the ability to motivate and coach colleagues to work towards shared goals.
- Excellent knowledge of a wide range of trusts & foundations, with a proven track record of securing significant grants.
- Proven experience of growing income through cultivating new major donors and/or corporate partnerships and achieving multi-year gifts or contracts.
- Track-record of success in developing community fundraising activities and in leveraging a range of income sources (including regular giving, etc).
- Ability to deal with people at all levels with empathy, tact and credibility.
- Ability to build and maintain relationships with a wide variety of stakeholders, both internally (colleagues, trustees, professional advisors) and externally (supporters, local and national organisations, corporates and high-value donors)
- Strong commitment to good governance and ethical practice in fundraising.
- Strong organisational and project management skills, with the ability to prioritise.
- Experience in using a CRM to maximise fundraising and engagement potential.

### Desirable

- Fundraising qualification or certification.
- Good understanding of, and strong interest in, developments in UK health and social care.
- An understanding of the issues affecting families living with a life-limiting condition.
- Experience of working with vulnerable people and understanding of safeguarding best practice.
- Good understanding of Microsoft Office packages, Google suite and desktop publishing packages.

## Why should you join us?

Join our dynamic and growing charity, where you'll thrive in an exciting and engaging environment. As a highly regarded organisation with an excellent reputation, we already attract interest from external companies (especially in the healthcare/pharmaceutical sector) with potential to invest in our mission, and we are looking to expand our internal team to enable us to maximise opportunities. We are proud to be a family-oriented charity experiencing financial growth and fuelled by an ambitious plan for expansion. Our dedicated team is deeply connected to our core audience, and their motivation stems from witnessing our profound impact on people's lives. Working alongside inspiring families, you'll see first-hand the incredible love and dedication they have. Join us today and contribute to making a lasting difference in the lives of those we support.



## How to apply

[Eastside People](#) is supporting Dravet Syndrome UK in recruiting for this role. [Please click here](#) to apply by submitting your CV and a covering letter indicating why you are interested in applying for this role and how you meet the selection criteria.

If you would like a call to discuss the role in more detail, please email Lucinda Shaw, [lucinda@eastsidepeople.org](mailto:lucinda@eastsidepeople.org) to arrange a convenient time. Having a call of this kind will not influence the success or otherwise of your application.

We want you to have every opportunity to demonstrate your skills, ability and potential; please contact us if you require any assistance or adjustment so that we can help make the application process work for you.

The closing date for applications is **Wednesday, 7 February, but the shortlisting and interviews will take place on an ongoing basis**, so we encourage you to apply early.

## Our commitment to diversity

As part of our ambitions to improve equality and diversity, we welcome applications for this role from those who identify under any of the protected characteristics under the Equality Act 2010, which include race, age, disability, gender, religion or belief, and sexual orientation.



# Eastside People

Eastside People  
Canopi  
7-14 Dover Street  
London  
SE1 4YR

0203 821 6174  
[eastsidepeople.org](http://eastsidepeople.org)

[Eastside People](#) is the trading name for Eastside Consulting Ltd. Company number: 4958922.