



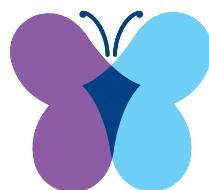
Dravet Syndrome UK

Head of Family Services

Candidate pack
October 2025



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DRAVET
Syndrome UK



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Introduction

I'm delighted to introduce this opportunity to join Dravet Syndrome UK as our Head of Family Services.

As both Chair of Trustees and a parent to a young adult living with Dravet Syndrome, I understand first-hand the challenges families face every day. Children and adults with Dravet Syndrome have very complex needs. They require 24/7 care for life. The condition is relentless. The isolation of living with a rare disease is profound. The constant battles to gain appropriate levels of support are exhausting. A diagnosis of Dravet Syndrome therefore has a huge impact, not only on the individual, but also parents/carers, siblings and the whole family.

That's why the Head of Family Services role is so important. We're looking for someone who can take the strong family support offer that we already provide and elevate it further.

Since our founding in 2009, we've grown from a small group of parents seeking mutual support into the only UK charity dedicated solely to improving the lives of families affected by Dravet Syndrome, with nearly 600 families registered with our charity.

The external environment has also changed significantly in recent years. With new treatments becoming available and growing awareness of Dravet Syndrome, this is an exciting time to be joining us.

In particular, the Head of Family Services will play a crucial role in delivering two of our four strategic objectives: Every Family Counts and Empowerment of Families.



This means that our family services are representative of the needs of every UK family living with Dravet Syndrome, that we are advocating for the rights of families with key stakeholders (including social services and local authorities), whilst also equipping those families with the knowledge and tools they need to navigate complex health, education and social care systems with confidence.

If you're passionate about making a real difference to families affected by rare disease, if you understand the power of peer support and empowerment, and if you have the leadership skills to grow and develop our services, I'd love to hear from you.

Charisma Recruitment are managing this process on our behalf and will be delighted to discuss the opportunity with you further.

I look forward to welcoming our new Head of Family Services to the team.

Galia

Galia Wilson
Chair of Trustees

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About us



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Background

Dravet Syndrome UK was created in 2009 by a group of parents who came together looking for support, resources and information relating to a rare, little known neurological condition called Dravet Syndrome.

Dravet Syndrome is a rare, life-long and life limiting neurological condition. It encompasses epilepsy (seizures are frequent, severe, often prolonged and rarely controlled), intellectual disability and a spectrum of co-occurring health conditions. These can include autism, ADHD, challenging behaviour and difficulties with speech, mobility, eating and sleep.

Around 1 in 15,000 babies in the UK will be born with Dravet Syndrome. It is estimated that there are around 2,000 people living with Dravet Syndrome in the UK.

Every child or adult with Dravet Syndrome is different. They share the key characteristics of the condition, but the range and severity of symptoms (especially the non-seizure aspects) vary from person to person. However, for all, the condition is complex and can be unpredictable. There is also a high mortality risk with Dravet Syndrome; sadly around 15% of children do not survive into adulthood.

Dravet Syndrome UK is an independent charity and the only UK organisation dedicated to improving the lives of those affected by Dravet Syndrome. We are a team of nine staff and five Trustees. We are also privileged to work with a world-class Medical Advisory Board, whose guidance helps inform our activities.

Our mission is to bring hope to families living with Dravet Syndrome through support, education and medical research. In 2021, we launched our first long-term strategy - a roadmap to guide our mission and enable us to reach more families, educate more professionals and fund more research.



Activities and support services with Dravet Syndrome UK includes

- 1:1 emotional support and practical advice via our Family Support Manager
- Non-means tested grants for equipment or assistance including: a seizure monitor fund, 16 plus adult assistance fund, a bereaved families fund, grants to support families attending the annual Family Weekend Away
- Annual Family Weekend Away at locations such as Center Parcs to bring together families and siblings living with Dravet Syndrome
- A private, DSUK-moderated online forum to overcome isolation and support a sense of community
- Literature and information, including our 'Family Guide', empowering families with knowledge, advice and insights on all aspects of living with Dravet Syndrome
- A biennial conference for parents/carers, including the latest information about Dravet Syndrome with presentations from our Medical Advisory Board and workshops

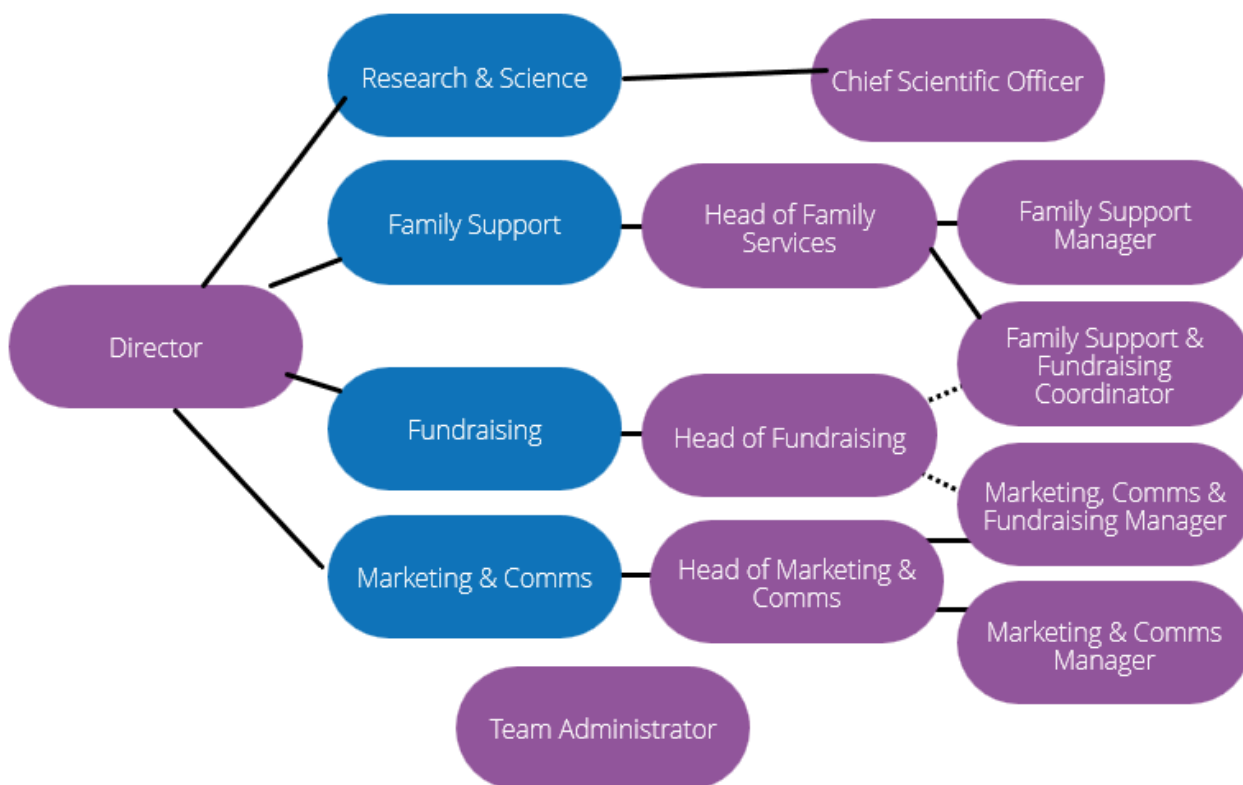
We also educate professionals to raise awareness and further understanding and fund medical research.



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About us

Team structure



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Job description



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Role details

Job title	Head of Family Services
Responsible for	2 staff
Location	Fully remote
Hours / Contract	24 hours per week, permanent
Salary	£44,000 - £50,000 full time equivalent



Responsibilities

The purpose of this role is to drive and further develop Dravet Syndrome UK's family-facing strategic objectives including - 'Every Family Counts' (reaching and supporting more families affected by Dravet Syndrome) and 'Empowerment of Families' (enabling families to know their rights and encouraging self-advocacy).

This is a newly created role to support growing caseload of family needs in accessing support to which they are entitled in living with a complex and life limiting condition. Experience of working in the disability sector (with children and/or adults) is essential.

The role requires good working knowledge of the relevant statutory and regulatory frameworks, relevant organisations and agencies involved in supporting families living with complex needs/disabilities, and experience of an appropriate range of professional interventions.



Specific duties

Every Family Counts

- Lead on the development of activities targeting allied professionals (e.g. social care, special needs educators, care managers) and decision-makers involved in providing support services, with the goal of reducing barriers families face when applying for support from local authorities (e.g. ECHPs, social care) and/or NHS continuing healthcare
- Develop our support and services for adults and children living with Dravet Syndrome and their caregivers

Empowering Families

- Lead the further development of our work to help families understand their rights and feel confident advocating for the support they need (i.e. above and beyond what is provided now such as support letters, signposting etc)
- Create practical resources and guidance for both families and professionals (such as social workers and healthcare staff) to help families access appropriate support
- Develop an approach for assessing families' support needs and providing specific advocacy guidance to those need it, drawing on knowledge of relevant laws and statutory services, including those relevant to living with a complex disability

Leadership and Reflective Practice

- Lead and develop the Family Support team, identifying training and development needs
- Provide structured support and reflective practice sessions for the Family Support team to help them manage the emotional demands of supporting families in distress

Safeguarding

- Be the safeguarding lead for charity and proactively follow up on cases where there are potential safeguarding concerns
- Undertake assessment and planning for safeguarding in complex cases, and help others with safeguarding skills

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Job description



Education

- Work with the wider team to ensure our educational activities meet the needs of parents, carers and the wider community, particularly by keeping signposting and support information up to date and relevant to families living with Dravet Syndrome

Other responsibilities

As required:

- Attend external events, including DSUK's annual weekend away and bi-annual DSUK Conference
- Keep up to date with developments in best practice in family support
- Comply with DSUK policies/procedures, including Safeguarding and Data Protection



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Person specification



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Experience

Essential

- Previous experience of a working environment involving families with disability and/or complex needs (minimum 5 years' experience) i.e. in at least one of the following working environments: social care, health care, special needs education, disability law and/or family support in a similar organisation
- Detailed working knowledge of disability law (for children and adults) and other relevant statutory and regulatory frameworks (e.g. social care, EHCP and continuing healthcare) with proven ability to negotiate, mediate and interpret on behalf of service users (ideally knowledge across all four UK nations)
- Demonstrable expertise and advanced training in all aspects of safeguarding for children and vulnerable adults
- Experience of line managing staff for a minimum of 5 years, with the ability to motivate and coach colleagues to work towards shared goals
- Experience of effective working in a remote environment

Desirable

- Experience of working in related voluntary sector or statutory organisations.
- Experience of multidisciplinary working
- Experience and training in bereavement support services



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Person spec



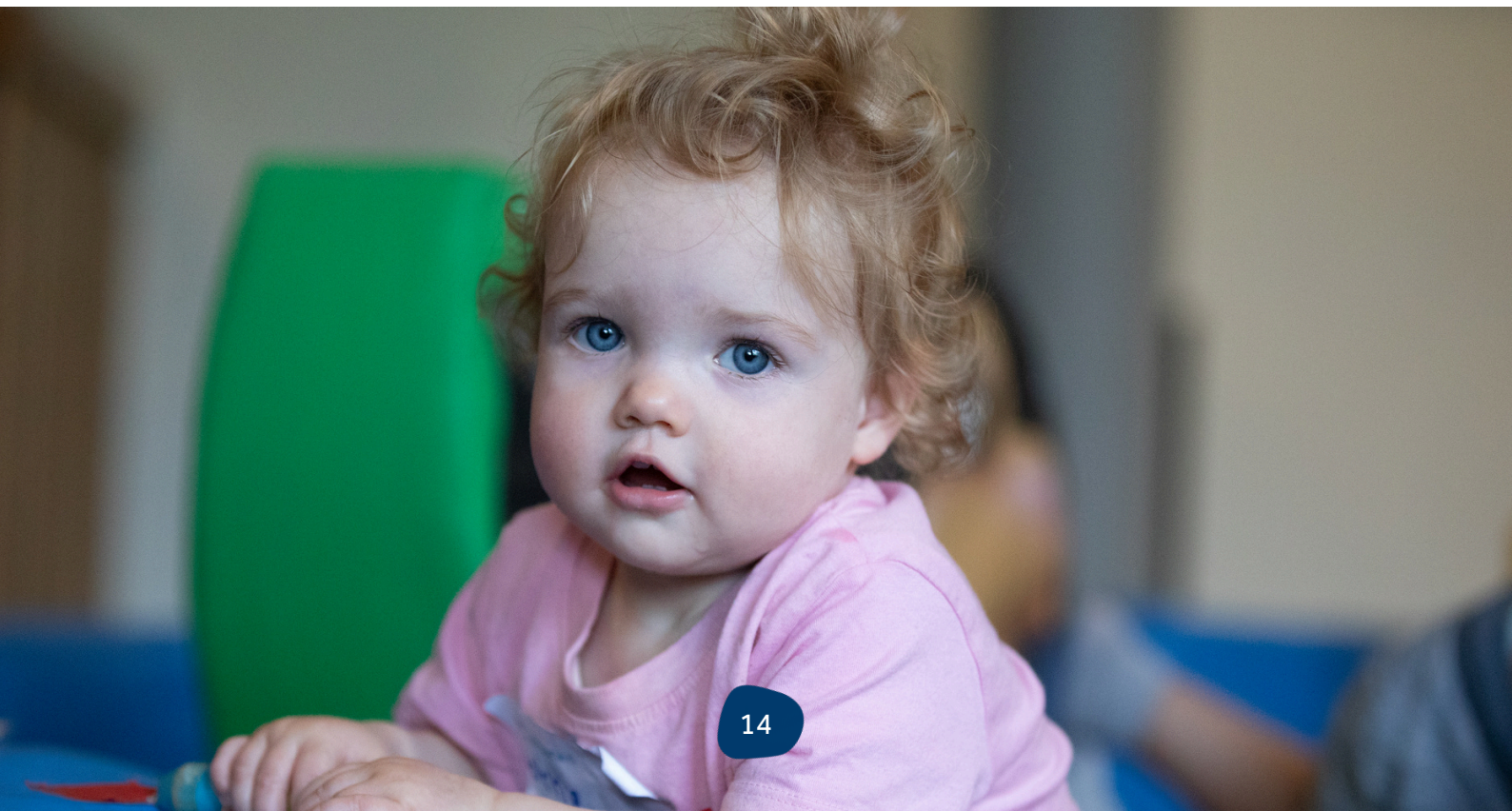
Skills

Essential

- Have a warm and approachable manner with the ability to build trusting relationships quickly with people from diverse backgrounds and facing difficult circumstances
- Confident communicator with the ability to articulate complex issues clearly and persuasively in written and verbal formats.
- Demonstrable ability to anticipate, assess and manage risk, including in more complex cases, and support others to develop risk management skills.
- Proven ability to provide high quality professional supervision (reflective practice) to qualified and unqualified staff, and to use supervision to maximise personal effectiveness and professional development
- Excellent organisational and teamworking skills to be able work remotely, manage and prioritise a varied caseload and delegate effectively

Desirable

- Critical awareness of current issues and new evidenced-based practice research.
- Confidence in working with complex medical or scientific terminology



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How to apply



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How to apply



Dravet Syndrome UK are working exclusively with Charisma Charity Recruitment.

Your application should be submitted through the [Charisma website](#), and include:

- A comprehensive CV
- A supporting statement, explaining how you believe you match the requirements of the role.

For an informal and confidential discussion about the role, please contact:

Sandra Smith, Associate Director of Charisma Charity Recruitment on 01962 813300 or email info@charismarecruitment.co.uk.

Charisma welcome and encourage expressions of interest from people of all backgrounds. We do not discriminate on the basis of disability, race, colour, ethnicity, gender, religion, sexual orientation, age, veteran status or other category protected by law.

Closing date: 9th November 2025

Charisma interviews must be completed by 12th November 2025, prior to shortlisting.

Interviews with Dravet Syndrome UK: TBC





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