



DRAVET  
Syndrome UK

Hope for families with life-limiting epilepsy



# DSUK 2025 Impact Report

In 2025, we were proud to support

**2,000+**  
beneficiaries

**568** Children and adults living with Dravet Syndrome

**877** Parents and Carers

**587** Siblings

**2**

**Family gatherings** hosted in London and Chesterfield thanks to funding from **National Lottery** and **Jeans for Genes**, with more planned in 2026!



 **Chesterfield**



**64**

Families attended our **Family Weekend** at Center Parcs, with a total of **300 attendees**.



# Every Day In May for Dravet



498

Participants in our annual **Every Day in May for Dravet** fundraising campaign, including 399 adults and 99 children.

£120,000  
was raised for DSUK

as a result of our incredible fundraisers **completing 2k or 5k** every single day in the month of May!



350+ people attended

our DSUK Conference across two days, including **228 on our Parent/Carer Day** and **171 on our Healthcare Professionals Day**.

570 health professionals

signed up to our **Health and Care Professionals newsletters**, staying up to date with essential updates, research and events in the Dravet space.



12 medical meetings

attended by **DSUK representatives**, including BPNA, RCPCH, European Dravet Conference, ICE, ILAE, AES and various research meetings.



## 6 new resources produced

including our Transition Guide, Schools Guide, two guides for families and professionals on accessing mental health support, a paramedic and ambulance resource pack, and a template letter for GPs.



## 30 16+ assistance grants

were provided, funding items of equipment or assistance that will improve the life of a young adult with Dravet Syndrome.



## 78 seizure monitors

funded, including 46 monitors and 32 fingertip oximeters.



## 3 bereavement grants

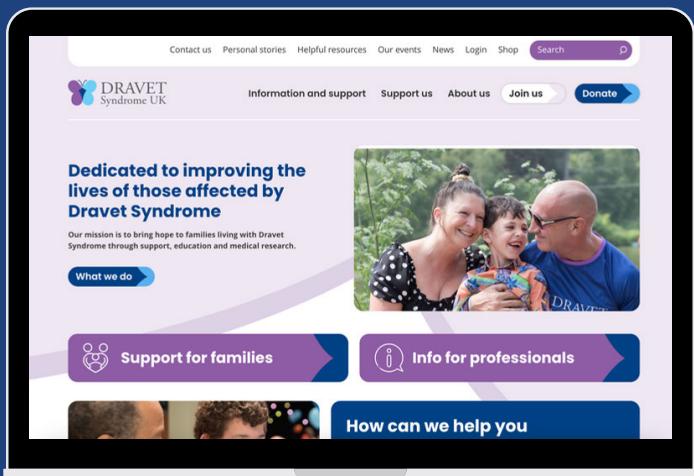
of £1,000 provided to families within six months of losing a loved one to Dravet Syndrome.



109

items of media coverage raising awareness for Dravet Syndrome and our charity's work, **including 30 items on national TV, radio or in print.**

**1.4 million views**  
across our social media channels and an **increase of 2,047 followers.**



**71,000**  
**website visits**  
in 2025, compared to 37,000 in 2024, following the launch of our new website in February 2025.



We welcomed **Ceri Hughes** as our new **Chief Scientific Officer** thanks to funding from the Chan Zuckerberg Initiative through their Rare as One grant, **accelerating our research programme** and enabling us to put patients and families living with Dravet Syndrome at the heart of research.



We have also been lucky enough to have worked with some incredible partners and funders in 2025, as well as receive support from so many inspiring fundraisers. Without them, none of this work would have been possible.

Chan  
Zuckerberg  
Initiative 

St  
James's  
Place

JEANS  
FOR  
GENES

[XTX]  
MARKETS

Share  
Gift

 **COMMUNITY  
FUND**

**The Daily Thomas**  
Charitable Fund 



***On behalf of our team and trustees, thank you for  
helping us to make such an impact in 2025.***

In 2026, we're looking forward to more family gatherings, Every Day in May for Dravet, our annual Family Weekend at Center Parcs, DSUK being represented at the London Marathon, and so much more.

**Here's to a hopeful and inspiring year ahead!**



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