



Every Day in May for Dravet 2025

Communications Pack

[1st May- 31 May]

What is Every Day in May for Dravet?

Now in its fifth year, the Every Day in May for Dravet challenge was set up in 2021 by Tamara 'Tats' Ward when she was unable to visit her seven-year-old nephew Dominic during COVID, who lives with Dravet Syndrome.

As in previous years, we are challenging people to walk, run, swim or cycle 5km or 2km each and every day in the month of May. You can do it however, whenever and wherever suits you, mixing it up as much as you like.

The aim of the campaign is to raise vital funds and awareness for all those individuals and families living with this complex and rare condition - affecting an estimated 1 in 15,000 births in the UK alone.

Since 2021, the event has grown tremendously, from 40 participants that first year to 450 adults and children taking part in 2024 from all over the UK.

This year, we're hoping to smash our 2024 success with more participants raising even more awareness and funds!

Watch our [Impact Video 2024](#) to find out more about our work.

Supporting Every Day in May on Social Media

To make a big impact and ensure our message is heard far and wide, we'd love for participants of Every Day in May to share their activity on social media. To help with this, we have put together some suggested copy for you to share and the various hashtags we plan on using alongside our campaign.

Dravet Syndrome UK Social Media Handles

Be sure to tag in your updates so we can share and cheer you on!

Instagram: @dravetsyndromeuk

Facebook: @Dravet Syndrome UK

LinkedIn: @Dravet Syndrome UK

Campaign Hashtags

#EveryDayinMayforDravet #EveryDayinMayforDravet2025

#EDIM2025 #DravetSyndromeUK

Useful Links for Education

About Dravet Syndrome: <https://www.dravet.org.uk/about-dravet-syndrome/>

What do we do at Dravet Syndrome UK:
<https://www.dravet.org.uk/about-us/what-we-do/>

Dravet Journey Stories: <https://www.dravet.org.uk/personal-stories/>

Little Moments Matter Video: <https://www.youtube.com/watch?v=6VICedy66QY>

Every Family Counts Video: <https://www.youtube.com/watch?v=Bilgb-bcuiw>

Social Media Copy Suggestions

Instagram/Facebook	Caption copy
EDIM Kick Off (1st May)	<p>Every day this month, I will be [insert how you're participating] as part of the #EveryDayInMayforDravet challenge to raise awareness for Dravet Syndrome – a rare and devastating form of epilepsy that affects children, adults, and their families every single day.</p> <p>💜 Please take a moment to learn more, share this post, or sponsor my efforts: [JustGiving link]</p> <p>#EDIM25 #EveryDayinMayforDravet2025</p>
Halfway-through update	<p>I'm officially halfway through my #EveryDayInMayForDravet challenge, using every step to raise awareness for all of the families living with Dravet Syndrome. 💜</p> <p>With just a few weeks left to go, let's keep the momentum going - support my</p>

	<p>fundraiser here: [link]</p> <p>#EveryDayInMayforDravet #EDIM25 #EveryDayinMayforDravet2025</p>
The impact of your donations	<p>As many of you know, I am currently taking part in #EveryDayInMayForDravet and fundraising to improve the lives of all those impacted by Dravet Syndrome.</p> <p>To anyone kindly considering donating towards this cause, here is a video showing the impact that your vital donations can have:</p> <p><i>[Link to Dravet Syndrome UK Impact video here:</i> https://www.youtube.com/watch?v=JkqR0HEEwZM]</p> <p><i>[Link to Little Moments Matter video from Dravet Syndrome Awareness Month here:</i> https://www.youtube.com/watch?v=6VICedy66QY]</p>
Helping families like ours	<p>Dravet Syndrome isn't just a diagnosis — it's something our/my [family/child/sibling/niece/friend], [Name], lives with every single day.</p> <p>This May, I'm taking on a daily challenge to raise awareness and vital funds for Dravet Syndrome UK, a charity that's been a lifeline for families like mine.</p> <p>If you can spare anything — even the cost of a coffee — please sponsor me or share this to help spread the word. Your support means everything.</p>

	<p>👉 [Fundraising Link]</p> <p>#EveryDayInMayforDravet #EDIM25 #EveryDayinMayforDravet2025</p>
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LinkedIn	Caption copy
Individual fundraising	<p>This May, I'm stepping outside my comfort zone every day to support a cause close to my heart - @Dravet Syndrome UK.</p> <p>Dravet Syndrome is a rare neurological condition that impacts children from infancy, with seizures, developmental delay, and high medical needs.</p> <p>I'm proud to raise awareness and funds for a small but mighty charity making a real difference. Please consider supporting my efforts here: [link]</p> <p>#DravetSyndromeUK #EveryDayInMayForDravet #FundraisingForGood</p>
Team/Corporate Fundraising	<p>Team [Company Name] is joining forces for @Dravet Syndrome UK's #EveryDayInMay campaign!</p> <p>We're taking on daily challenges to raise awareness for this rare condition and fund vital support for affected families.</p> <p>Donate or learn more 👉 [link]</p> <p>#CSR #RareDiseaseAwareness #DravetSyndrome</p>

Social Media Graphics

Download our customisable social media graphics here and get posting!

<https://www.dravet.org.uk/support-us/fundraising-materials/>

SPREAD THE WORD!

Download our fundraising materials and spread the word about your fundraising campaign for Every Day in May for Dravet on social media.

