Winter 2025 Newsletter



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Sophia's Drama

Sophia is a 17-year-old student at the prestigious Brit School, who has life goals and big dreams: to be on stage, to be a mum, and to travel, in that order!



At the age of 14, Sophia began to lose the ability to walk, and was diagnosed with an extremely rare genetic condition called progressive pseudorheumatoid dysplasia, (PPRD), which Sophia explains "is basically fake arthritis. I'm missing a gene called CCN6 which is responsible for the renewal of new cartilage. It can cause the bones to become swollen and painful and they lose a lot of mobility".

Sophia currently uses an NHS provided wheelchair, but due to the progressive nature of her condition she needs a wheelchair which will self-propel and be much more lightweight.

The family discovered an active chair with a Yomper attachment which Sophia explains "kind of feels like you're floating. It genuinely feels like a part of me. It would be life changing to have. It would give me so much more independence, something I've not had for a long time!" The wheelchair and its motorised attachment costs £12,000 and is not available on the NHS, so that is why the family turned to Tree of Hope to fundraise, which they love for the fact that they wanted people to know "that this was a bona fide cause that we were raising money for. Obviously, the ability for UK taxpayers to add gift aid onto the donations, which we couldn't do as individuals, is a big bonus."

After just one week of fundraising, Sophia's campaign reached £6,000, 50% of her target. Andrianna, Sophia's mum, has been "left speechless at times, when I've seen the donations flooding in and [knowing] people support Sophia, so that she can realise her dreams."

Sophia's dreams feature a career on stage: "stage is exactly where I want to be 24/7, all the time, I just love it. If I have a new wheelchair, it would make it easier for me to focus on the acting side of things, rather than focusing on getting around".

For her parents Sam and Andrianna, they simply say "we would like to think that despite her disability, she will tick off all her hopes, dreams and aspirations that she wants. She wants to be a stage actress. Well, good for her. Go for it, Sophia. Follow your dream, follow your passions. We will do everything in our power to support that."



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Our News

In September, we were honoured to be invited to the **Wards Children's Awards for 2025.** It was a humbling and fun filled event, recognising the bravery of so many children across Kent faced with many challenges, much like the children and young people we support at Tree of Hope.

Over the last two years, **Wards have raised over £40,000** for Tree of Hope, in the form of fancy dress competitions, raffles, quizzes and challenging walks, runs and cycle rides. If you want to know more about Charity of the Year adoptions and Corporate Partnerships, we would love to hear from you on **partnerships@treeofhope.org.uk**

Thank you to **Holmewood House School** in Kent, who, this September wrapped up their Charity of the Year adoption with us. Over the years, the school raised just over £5,500, which is amazing!

As part of our adoption by the **Tunbridge Wells Inner Wheel**, our Family Support Officer Caroline attended one of their monthly meetings to share stories about the families we support. The group is now well on its way with fundraising and in early November held a coffee morning that raised over £800 for Tree of Hope!

For another year, Tree of Hope will be **gifted Christmas presents for our children and their siblings living in Kent and Sussex**, all thanks to the **Bluewater Shopping Centre Giving Tree**. Not only that, but Wards Estate Agents will be volunteering at the **Christmas Wrapping Station at Bluewater** on Thursday 11th December to wrap up all of your Christmas gifts, to save you precious time. All donations on the day will come directly to Tree of Hope!



Trusts and Foundations

We are grateful to be supported by a number of foundations including the Jack O'Donnell Foundation who, this year have supported a further 13 Tree of Hope families by providing them with a grant towards various pieces of equipment, therapies and communication devices.

A special thank you also to the Medicash
Foundation who awarded Tree of Hope a grant to
support our Family Support work in the North West.
These vital funds will help families receive tailored
fundraising support and campaign development.



Hackney Half Marathon – Quickly becoming the highlight of London's running calendar, run the Hackney Half on **17th May 2026.**

5km Women's Series – Run 5K through the Queen Elizabeth Park in London on the **8th March 2026.**

Colchester Stampede 10km – Run amongst some of the world's most majestic animals in Colchester Zoo on **17th May 2026.**



Hugh's New Wheelchair

15-Year-Old Hugh was born with an extremely rare condition called FoxG1 syndrome, which means he has complex health needs and suffers from life-threatening seizures. He needs 24/7 care for all aspects of life, however, he doesn't let his condition affect his love for rock music and heavy metal, as he's known to jam to his own music on the guitar!

Hugh's family came to Tree of Hope to raise £33,000 for the Permobil F5 Corpus power chair, which would give him the ability to move independently for the first time in his life. The chair would allow him to rise to a standing position which would give him so many opportunities that most people too often take for granted: standing up to cheer when his brother scores a goal, or standing during his favourite song at his next gig.

Quite incredibly, his family managed to raise OVER their target figure within 4-weeks of beginning their campaign, and Hugh is already loving his new chair, experiencing new things from a different perspective and going on adventures!



Matt's Henley Half Marathon for Salem

Salem's dad, Matthew, completed his first Half Marathon at Henley River on 30th August, all in aid of raising funds for continued therapies. Salem (also known as Lemmy) has cerebral palsy which means he's unable to walk unaided, but regular physiotherapy enables him to gain strength, and it gives him the greatest chance at being able to take his first independent steps.

Learn More

Matthew was inspired by Lemmy's strength and determination to get him across the finish line and was thrilled to raise a wonderful £2,080!

With speaker

Gurvinder Samra

Principal Lawuer



Join us for an **Education Law Webinar**

20 January 2026 | 18:00 to 19:00

Our Education Law experts focus on special educational needs and disability work specialising in Education Health and Care (EHC) plans including:

- Advice on the whole process of securing an EHC plan from start to finish.
- Expert advice on the legalities and evidence required to secure an EHC needs assessment and then to secure an EHC plan.
- Representing parents in appeals to the SEND tribunal
- Assessing the content of EHC plans and advise on whether they are legally enforceable and the quality of provision.
- How to secure changes to special educational provision including increases to therapy provision, teaching input and expertise and changes in school/college placement.

Dominic Smith
Dominic.Smith@slatergordon.uk
by I6 January 2026.





Lyra is a bright, smiley one-year-old with the most infectious grin, but she faces a range of developmental delays and complex medical needs, including profound hearing loss and a potential diagnosis of cerebral palsy.

Lyra is profoundly deaf, meaning she does not respond to sound at all. She may sense vibrations or very loud noises, but her brain cannot interpret sound signals. Mum, Hayley, explains that "her ears work fine, it's just her brain can't understand the sound at the auditory nerve, so it's somewhere in her brain that's stopping her from hearing sound."

It is because of Lyra's deafness, that Hayley has re-started learning British Sign Language (BSL) to help her communicate with her daughter. In addition to this, Lyra's nursery have been a wonderful source of support. "She has a British Sign Language (BSL) level six teacher, which is very rare to have in a nursery setting. She's signing all the time to Lyra in the class, so actually it's very beneficial for all the other children as well." The nursery also works closely with Lyra's teacher of the deaf to ensure an inclusive learning environment — from adjusting lighting and reducing background noise to encouraging eye contact when communicating.

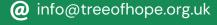
While Lyra understands signs, her limited hand movements (caused by a potential diagnosis of cerebral palsy) makes signing back difficult, so Hayley and her family are finding creative ways to help her express herself through various forms of communication, to see which works best for Lyra. This involves the family truly listening and responding to Lyra's cues and preferred methods of letting people know what she wants.

On top of this, Lyra's family are fundraising for ABM NeuroMovement and SwimLab therapy to improve her overall development and mobility, and to help her form new movement patterns and strengthen the connection between the brain and body. ABM NeuroMovement therapy costs £500 per week, with Lyra needing approximately four intensive weeks, and SwimLab costs £1,600 for the week. Take a look at how you can support Lyra, by scanning the QR code.

Need our help?

Our Family Support Team are on hand to help you through all stages of your fundraising by:

- Assisting with the creation and management of a Tree of Hope online fundraising campaign via JustGiving
- Regular fundraising support and guidance as well as tailored action plans
- Enabling each campaign to claim gift aid because it is part of our registered charity
- Giving greater exposure to campaigns nationally through PR support
- Support with managing funds and paying invoices



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