

Summer 2025 Newsletter



Jasmine was born with a rare and serious medical condition called Methylmalonic Acidemia (MMA) which affects her brain and muscles, making everyday tasks a challenge.

Jasmine has an adventurous and positive spirit, despite the many challenges that she's faced: She was born with a rare genetic condition called Methylmalonic Acidemia (MMA) which affects how her body processes certain proteins and fats, and can lead to a build-up of harmful substances in her blood.

Mum, Julie explains that "Jasmine doesn't stop making acid. If it's not treated, it basically corrodes and attacks the organs and the motion part of the body and breaks everything down until it will just stop working."

Due to her condition, Jasmine has to be on a very low protein diet and she also has a weak immune system. Any setbacks in Jasmine's health can cause development delays, but whilst these setbacks are one of the most challenging aspects to Jasmine's condition, her determination is one

of her most admirable qualities; Julie says that "she's always trying to push beyond the boundaries of what people say she might not be able to do."

To help improve Jasmine's motor control and reduce spasticity, her family are fundraising £5,800 for a Mollii Suit, a wearable, electrically stimulating suit. After trialling the suit last year, Julie said that "you could see a massive difference in her". After just one hour, she could sit up unaided and she could put both arms on the wheelchair.

The Mollii Suit needs to be worn for one hour a day to start with, and then a reduction of time wearing the suit follows in the following months, to give her the opportunity to move independently and be included in so many more aspects of life!

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Our News

Thank you to the **Hever Castle Golf Club's Ladies Captain, Fiona,** who hosted a Ladies Open on 14th May, raising a fantastic **£890** from a raffle held on the day!

Marcus and Pradeep, bar staff at Hever Castle Golf Club took on 100 holes of golf over the course of 24 hours from 8th-9th July in aid of Tree of Hope. The pair promised to run around the course if they reached their target, which they did before the event even took place! Thank you both for raising £2,300 for Tree of Hope!

Thank you to **AMS Group** for raising a wonderful £242 during their **team Snowdon Climb** on 20th June. Having heard of Tree of Hope through the support we provided for a local family, Daniel Rawden selected us as their chosen charity, saying "Tree of Hope's mission to empower families and support children is something that anyone and everyone can resonate with and support."

Thank you to **Christine and Mary from the Tunbridge Wells Inner Wheel** for picking Tree of Hope as their charity of the year adoption, which started on 1st July!

Interested in taking part in a challenge to raise funds for Tree of Hope? We will soon be offering places to a number of different events, including the Manchester Half & Marathon, Tough Mudders (across multiple locations) and the London to Paris Cycle – we will have an event to suit your needs! Email fundraising@treeofhope.org.uk to let us know what events you're interested in and we can match you to your dream event!



Peter Stebbings Memorial Charity

Trusts and Foundations

As always, our thanks go to the Trusts and Foundations who are supportive of the work of Tree of Hope. Special thanks goes to the Hospital Saturday Fund for their generous donation to support our Family Support Team, as well as Channel Ports Community Fund, Sackville Family Fund and the Owen Fund.

Our Family Support work in London and across the UK is also kindly assisted by a grant from The Peter Stebbing Memorial Charity, to whom we are very grateful.



Event Highlight

On Thursday 26th June, Tree of Hope hosted our Charity Golf Day at Hever Castle Golf Club. Guests enjoyed bacon rolls on arrival before heading out to play 18 holes of golf. Afterwards, they sat down to a meal, took part in a live auction, and celebrated the raffle prizes and the day's winners, including Stuart (Longest Drive), Alex (Nearest the Pin), Justin (individual winner), and the Shankaholics Anon team (overall winners). Huge thanks go to our sponsors – Pure Nails, Mayflower Washroom Solutions and The Merit Group, plus our fantastic volunteers, Richard and Fiona, and to Hever Castle for their warm hospitality.



Harry's Supporters' Skydive!

On 17th May, Harry's mum, Kim, and her group of dare-devil friends all did a Skydive in aid of Harry's campaign. Harry, who has cerebral palsy, needs to attend a 3-4 week intensive course of CIMT (Constraint-Induced Movement Therapy) to help him with his upper body movement, and give him greater independence.

Kim said that "the skydive was amazing! It was terrifying in the morning, but then in the afternoon when we were done, it felt amazing. We will definitely be doing another one!"

The skydive raised £695 online, and another £600 in cash donations!

Find out more about Harry here:



Thank You, Drusillas and Colchester Zoo!

Huge thank you to Drusillas Park and Colchester Zoo for inviting some of our local families to their Dreamnights in May and June!

The events were designed for seriously ill and disabled children, so they could come to the parks after hours for an evening of fun and inclusive entertainment, all whilst being treated as VIPs for the night!

The children got to enjoy character meet and greets, accessible sport workshops, a tasty BBQ and full access to the zoo. Our families all agree that the evenings gave them memories to last a lifetime!





How Can Orthotics Help?

At LOC, we provide a wide range of bespoke orthotic solutions to support children with cerebral palsy. Our orthoses are carefully designed to:

- Improve stability and balance
- Help manage muscle tightness and spasticity
- Support better posture and body alignment
- Promote greater independence in daily activities

Our orthotic options include:

- Ankle Foot Orthoses (AFOs) & Supra Malleolar Orthoses (SMOs): Help improve walking patterns and promote more efficient movement.
- Knee Ankle Foot Orthoses (KAFOs): Offer targeted support for significant weakness in the knees and ankles, improving standing and mobility.

- Gait Lab Assessments: In-depth motion analysis using advanced technology to guide orthotic design and ensure optimal fit and function.
- Agilik™: A groundbreaking, powered orthotic knee joint. Designed to assist children with crouch gait, the Agilik™ actively supports weakened quadriceps and hamstrings, helping to improve walking ability, posture, and overall mobility. The Agilik™ is the

only knee joint that can be incorporated into a KAFO with active extension and flexion through an actuator, offering unparalleled support and function for those with reduced leg strength.

If you're a parent looking for the best support for your child, our experienced team is here to provide expert guidance and compassionate care every step of the way. Find out more here:

www.londonorthotics.co.uk/



Connor Murphy was diagnosed with Genetic Alteration Variant of Uncertain Significance, labelled HIVEP-2, at 18-months old. It is neurological and affects brain function, meaning he has development, intellectual and physical delays, as well as hypertonia too.

The Murphy family are fundraising with Tree of Hope for home physio equipment and making home adaptations to accommodate specialist furniture. In order to provide this, they have been very successful with their fundraising events and challenges in particular. Each year the family plan to take part in running events, such as the Manchester half marathon, and also hosting a 'Gig in the Garden event'.

Dad, Ben believes that "with a run, it's such a simple thing to do because it takes away the planning. You train a little bit, take part, make everyone aware that you're doing it, and then just go and do it on the day". In addition to this, the Gig in the Garden is a longstanding tradition for the Murphy family, who have now dedicated it to Connor's fundraising campaign. The event includes music from local bands, a quiz, bake sales and raffles, and due to the family's strong community connections, Ben says that "every year it's just jam-packed"!

The Murphy family have utilised Tree of Hope's support by getting involved as much as possible, from "making the awareness video for Connor and getting involved with the PR staff who helped spread the word through local news articles and radio pieces. I don't think that would have been possible on my own. The reach that Tree of Hope has given us has allowed us to really be able to spread the word publicly".

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For families who are struggling, Ben encouraged them to use the Family Support Team, explaining that it "make[s] it a bit easier for us. They can sometimes do the legwork to make that first step, which is sometimes

the most difficult part". To get the fundraising ball rolling, Ben advises "finding a short amount of time, seeing what other people have done and then just finding that idea and proposing it."



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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