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Jake's Life Saving Treatment

16-year-old Jake is a talented artist who loves music, writing and going to the gym. He has high hopes of going to university and is really determined to do well in his studies, however, he has recently received a life-changing diagnosis of Friedreich's Ataxia which is a genetic, neuro-degenerative disease of which there is no cure.



Jake told us that "there was always something that wasn't right, but I never knew anything else, so I didn't know that it was different. It was my normal". His dad, Paul, explained that Jake's balance had been a bit of an issue for a number of years. Doctors attributed it to an imbalance in his feet – special insoles having been prescribed to deal with the issue. However, he recalls one particular day last June when Jake "just started lurching sideways whilst we were walking to the shops, and I just thought we need to go to the doctors – that's when all the tests started."

After many rounds of blood tests, Jake was diagnosed with Friedreich's Ataxia just before Christmas 2025. As well as affecting mobility, balance and co-ordination, the condition can also cause sensory, sight and hearing loss, and can also affect the heart. Up until recently, there was no treatment available for Friedreich's Ataxia, however, hope has come in the form of a breakthrough

drug, Omovaloxolone, a course of tablets that, as Paul explains "is medically proven to slow down, arrest, and sometimes even reverse, to a degree, the progression of the disease. It's been passed as safe by all the major governments, [including the Medicines and Healthcare products Regulatory Agency (MHRA)], but whilst available in the EU and North America, it is incredibly frustrating that we can't gain access to it in the UK".

In January 2026, Jake's dad came to Tree of Hope to raise £300,000 to purchase the medication privately and to give Jake a chance of achieving his dreams for the future. Tree of Hope have been on hand to offer fundraising advice as well as PR and marketing support which Paul says "does help lessen the burden a little bit. If you've got an idea, to be able to sort of bounce off someone and to get the message out there, to have people supporting us like that is, well, it's wonderful."

The family have been blown away by the generosity of friends, family, strangers and local businesses, in the form of donations, offers of fundraising venues and auction prizes, as well as musical support from friends who have helped Paul produce a charity single which is due to be released soon.

Sharing advice on what helped Paul with fundraising, he said that "What I was saying to people is, can you share the page with as many people as you can? Social media is very powerful, but even if you can't donate, if you've got a good idea or you've got a skill or a talent or something that you can bring to the table, there's no bad idea!" Paul and Jake said that "I just want everyone to know how thankful we are. We just need to keep it going really – it's such a huge target to get to, but we will, we'll get there."





LOC's Festive Bakes!



Wards – Bluewater Wrapping Station

Our News

Thank you to the amazing team at **London Orthotics Consultancy** for their Christmas fundraising! The team baked some festive cakes to sell raising **£900** after being match funded!

Thank you, **Key Construction** for supporting us with our very first clothes bank at the new M&S development site in Tunbridge Wells! If you know of a site that might be suitable for us to locate a clothing bank, please do get in touch with us on **fundraising@treeofhope.org.uk**.

We were once again involved in the **Bluewater Giving Tree** this year. With thanks to Bluewater customers, we were able to surprise **29 children in Kent** with Christmas gifts, kindly delivered by our long-standing supporters **Aylesford Couriers**. This year, we also took part in the **Bluewater Wrapping Station** for the first time, with brilliant support from corporate volunteers at **Wards Estate Agents**.

Well done to Tree of Hope's Marketing and Communications Manager, **Steph**, who ran the Tonbridge 5K last year to raise **£340** for Tree of Hope. **If you're interested in taking on a personal running challenge whilst raising funds for Tree of Hope, we have a really exciting calendar of events that you can register for. So, if you lost out on your London Marathon spot, take a look at some alternatives, here:**



THE GRACE TRUST

Trusts and Foundations

Thank you to The Grace Trust!

"The Grace Trust was delighted to award a grant to Tree of Hope in recognition of the vital work they do supporting children and families during incredibly challenging times. Their compassionate and practical approach helps families access treatment and care that might otherwise be out of reach. The Grace Trust is funded by donations from the Plymouth Brethren Christian Church community, and we are pleased to support organisations like Tree of Hope, whose work aligns so closely with our values of care, generosity, and making a real difference."

Tree of Hope
Charity Golf Day
 5th June 2026
Nizels Golf Club
 Kent
 TN11 8NU

Event Opportunities

Join Tree of Hope on Friday 5th June 2026 at Nizels Golf Club! You'll be greeted with breakfast rolls and tea/coffee before heading out to play 18 holes of golf. On return to the club house, you'll be treated to a 2-course meal, a prize giving ceremony, raffle prizes and the live auction. This Stableford competition requires teams of 3 or 4, with places costing **£100** per person.

To book your place, please contact **karen.warner@treeofhope.org.uk** for your registration form!



Amy Rose has more freedom with her new Hoist



Amy Rose's Molift Hoist

11-year-old Amy Rose has athetoid/dyskinetic cerebral palsy and has been fundraising with Tree of Hope since she was a tiny baby for various therapies and equipment to help make life as easy as possible. Amy Rose is a wheelchair user, and as she gets older and bigger, it has become harder for her family to safely lift her out of her chair to access things that many people take for granted, like getting into the bath, or moving from her chair to her bed.

However, recently, mum, Ceri was able to use some of their hard raised Tree of Hope funds to purchase a Molift hoist for Amy Rose, which she describes as "an absolute game changer" which she has "wanted for so many years." The portable hoist is as light-weight and as compact as possible, meaning that she "will now be able to hoist Amy onto a picnic blanket in the garden, or let her rest/stretch on the sand on a blanket" on the beach. Ceri is so appreciative to "anyone who ever donated/ did a sponsored event to help us."



Get Support



Emma Celebrates 10 Years!

Our wonderful Head of Fundraising (Trusts and Foundations), Emma, has just celebrated 10 years at Tree of Hope. She said that she is motivated by:

"The amazing and resilient children and young people, and their incredible families who are often going through circumstances most cannot even imagine. When parents share how much their child is gaining from being able to access the right healthcare at the right time, and how much this has changed their lives, it is very emotional – every single time. Connecting philanthropists and donors with a cause that they share goals with and can really make a difference with, is an absolute joy."



Alfie Lewis' 10k

Alfie's little brother, Noah, has Niemann–Pick Disease Type C1 (NPC1), a progressive and life-limiting condition. This condition affects Noah's physical, neurological and cognitive function and he will need to be supported throughout his life, so Alfie kicked off the family's fundraising calendar with a 10k run, alongside friends Stanley, Luca, George, Jake and Liam. They completed the challenge in just 49 minutes and 36 seconds and raised £2,996 which will go towards ongoing therapies and specialist equipment to support Noah. There are even more fundraisers to come in the form of the Brighton Marathon and a Ben Nevis Hike!



Learn More



Stanley's Ninjas

Stanley is a typical nine-year-old who wants to explore and experience everything life has to offer. However, he lives with cerebral palsy, which affects all four of his limbs and means he relies on a wheelchair every day.

As Stanley has grown older, his previous NHS wheelchair “wasn’t really meeting his needs. It was very heavy, very cumbersome and he wasn’t able to move easily in it, so we were highly recommended to a company called Recare in Oxford,” explains his Grandma, Teri.

Recare identified a specialist off-road wheelchair tailored specifically for Stanley. With interchangeable wheels for different terrains and enhanced manoeuvrability, it has would transform what he can access.

However, due to the specialist nature of the chair, NHS funding was unavailable and the family needed to raise £6,730 to secure it. Teri applied to comedian Jason Manford’s ‘Charity Ninjas’ initiative, where thousands of followers donate £2 to a selected cause. Having been selected, Teri’s “phone started pinging at 10pm, and it was still pinging two days later” as donations flooded in. Amazingly, “within 28 minutes, we had every penny we needed. 28 minutes! It was just phenomenal and it was a fantastic of start to the year”.

Since receiving the wheelchair, Stanley is “a different child. The change was instant... The joy on his face was amazing.” Stanley now “is able to do everything, go everywhere, and there’s no limits to what he can access”.

With Stanley now enjoying greater freedom outdoors, the family’s next fundraising focus is adapting their home. Their current house “is not perfect for a disabled person. There are no houses out there really that are built perfectly for disabled people”, so plans include adding a downstairs bedroom and wet room to create a fully accessible space where Stanley and the whole family can thrive. With a Disabled Facilities Grant not covering the costs, a further £40,000 is needed, but you can contribute to the costs of the adaptations by scanning the QR code above!

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

@ info@treeofhope.org.uk

www.treeofhope.org.uk

01892 535525

treeofhope.childrenscharity

www.linkedin.com/company/tree-of-hope

@treeofhopecc