



# Tree of Hope

*Transforming the health of  
sick and disabled children*

FEBRUARY 2021  
**newsletter**

Inside this issue

#HelpforEdward

Supporting Paws Partnership

PANS PANDAS awareness



Registered with  
**FUNDRAISING  
REGULATOR**

Tel: 01892 535525  
[www.treeofhope.org.uk](http://www.treeofhope.org.uk)

Registered Charity in England and Wales No. 1149254 / Scotland SCO42611





As we find ourselves in the midst of a third lockdown and into a new year we are working hard at Tree of Hope to continue to offer help and support wherever it may be needed to our families and suppliers.

The needs of our children continue, and we have been incredibly successful in the last few months getting both national and local media for many of our campaigns that have helped boost campaign funds, hit targets and get much needed operations, therapies and equipment that make life-changing differences.

If you feel your campaign could do with a boost, call us and we can help, we often appear in the piece alongside you, whether on TV, Radio or in the press, and will help all the way to calm any nerves. Even more so now, people are craving stories that are feel good and help lift us from the current issues faced by all due to the pandemic and we get great feedback from our PR as families are able to explain what they need and why, tapping into community feelings of wanting to help.

Our online programme of events was particularly well received over Christmas, and we continue with these for the foreseeable future- look out for Valentine and Easter events, some specifically for children- just the thing to book up for and take a break from home schooling.

As always if you need our help and support, or know a child who would benefit from fundraising with us, please do contact us and we will do the very best we can to help. Do follow us on social media and like and share our content- this helps many more people to become aware of our vital work supporting the NHS to deliver the best healthcare it can to children and young people across the UK.

Please do contact us with any thoughts or comments on this issue at [Info@treeofhope.org.uk](mailto:Info@treeofhope.org.uk) we would love to hear from you.



Kind regards

**Gill**

Gill Gibb

## in this issue

- 3 Hello!**  
Welcome and Centrobed case study
- 4 A Little Man with A Big Plan**  
Parents having to adapt care plans in the pandemic
- 6 Supporting Paws Update**  
Partnership success in continued support for families
- 7 Declutter & Donate!**  
In need of a clear out? See how you can help!
- 8 #HelpforEdward**  
Raising the awareness of SMA
- 10 Fundraising News**  
Updates and News
- 14 PANS PANDAS UK**  
A condition that may be more common than we think
- 16 Importance of Specialist Equipment**  
How equipment assists children in their free time
- 17 Regular Giving**  
How to regularly donate
- 18 How We Help**  
Disabilities and Conditions we support



@treeofhopecc



[treeofhope.childrenscharity](https://www.facebook.com/treeofhope.childrenscharity)



[www.linkedin.com/company/tree-of-hope](https://www.linkedin.com/company/tree-of-hope)



@treeofhopecc

Tree of Hope, Salford House, Salford Terrace, 19-21 Quarry Hill Road, Tonbridge, Kent, TN9 2RN

Telephone (Head Office): 01892 535525  
Email (General enquiries): [info@treeofhope.org.uk](mailto:info@treeofhope.org.uk)  
Marketing Email: [marketing@treeofhope.org.uk](mailto:marketing@treeofhope.org.uk)

© Tree of Hope 2016. All rights reserved

Tree of Hope is registered in England and Wales as a charitable company limited by guarantee Company No 08184807. Charity No 1149254

[www.treeofhope.org.uk](http://www.treeofhope.org.uk)

## HELLO



Hoping everyone has settled into 2021 as best as possible and those home schooling schedules are going as well as possible. Hang in there everyone! You've got this!

We know how challenging things continue to be for families needing to continue

shielding and we're continuing our support for families to access alternative therapies and equipment at home, as well as providing lots of fundraising guidance to help navigate alternative and virtual ways of fundraising for the time being.

I have been completely inspired by our families,

some of whom have gone from strength to strength despite the challenges. Creativity is paving the way!

Take a look at our Fundraising update on pages 10 & 11. Our Lent challenge will be sure to keep you entertained!

Keep safe everyone!  
Georgie, Editor

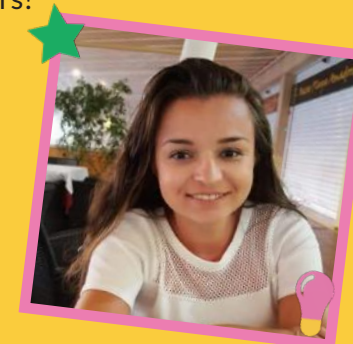
## A Warm Welcome!

Stephanie has joined our team as our Marketing & Family Support Officer working with Georgie & Caroline and brings a great background in social media and content, with a passion for helping others!

"I'm so pleased to be joining the Tree of Hope team, who have been so friendly and welcoming, despite having only met most via zoom! I have always wanted to be able to help people, so when this opportunity arose, I knew it was something

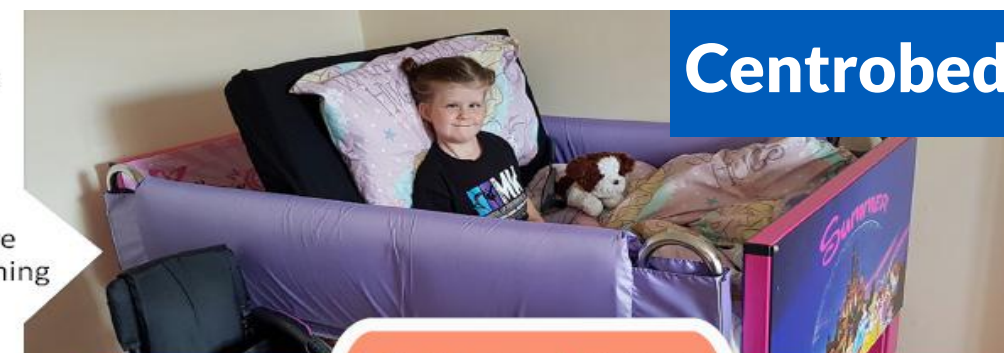
I had to go for. During such challenging times for everyone, I am so pleased to be able to offer support to others who may be struggling and I really hope I can make a difference by making life that little bit easier for families along their

fundraising journey. In my spare time, I love anything creative - from cross stitching to painting. I am also a massive fan of classic films and musicals and think that The Sound of Music is the best film ever made!"



"All in all the bed has made night times one less worry for us and she now enjoys getting into her bed. When a profiling bed was first mentioned we imagined a hospital bed, we could never have imagined she would have something that looks this wonderful.

So thank you to everyone at Centrobed for making our daughters dreams a reality."



**Centrobed**

### Flores Cot



High-sided wooden surround with a profiling bed frame. This specialist piece of equipment has been created to give children a fun and safe environment.

### Caribbean – A Unique Childrens Turning Bed



Fully profiling bed that turns, has independent leg movement and will grow with the child. This specialist bed has a wide range of movements available that can help children reposition and find comfort with minimal intervention.

### Scotia Cot



The attractive Scotia cot with its high/low and head raising functions compliments a traditional nursery environment.

Centrobed produce specially designed products for children. Beds can be made to fit the child taking into consideration their own specific needs.

A paediatric bed needs to fit the child and ours certainly do.

t 01233 635353 e [sales@centrobed.com](mailto:sales@centrobed.com)

[www.centrobed.com](http://www.centrobed.com)





# A Little Man with a BIG plan!



Smiling Eddie!



The past twelve months have proven to be a challenge for so many families, with therapy sessions cancelled and educational settings forced to close due to the ongoing pandemic. For children like Eddie, these vital services offer life changing support for physical and educational development, and their closures have left many families struggling with support. However, determined to make the best of a bad situation, Eddie's mum, Linsey, has strengthened ambitions to fundraise for specialist home equipment and therapy, which Eddie will be able to use long beyond this current COVID world.

When Eddie was four months old, he suffered a traumatic brain injury leaving him blind with cerebral palsy, epilepsy, sensory processing disorder and Autism. Despite doctors saying that he may never be able to talk, walk or sit unaided, determined Eddie has time and again proven them wrong, by reaching many milestones his family initially feared he would never reach. With the help of various therapies combined with his attendance at a special needs Nursery, Eddie was thriving. He was receiving therapy "every 6-8 weeks" to help build his core

strength, and Nursery provided an environment which encouraged social development. Linsey explained "His enrolment at Nursery was a significant step in his little life. He was doing really well with interacting with other adults." Linsey went on to say "he doubled his vocabulary at nursery - that's what can happen when he has the right input. We know he has the ability!" Since its closure, mum Linsey started to notice Eddie's development deteriorate. "There are regressions in his behaviour, and he is back to square one in his interaction with other adults [and has

since] missed out on a lot of progress". Over the last twelve months, families have had to find alternative ways to help their children, Eddie has accessed alternative online sessions, including speech and language therapy via zoom. Linsey explained, "it has given the tools to help him [as well as] the opportunity to of course correct what I'm doing with Eddie." Linsey also explained Eddie was missing out on face to face social interaction, which is so vital to him, due to his vision. Linsey told us "When he was in a language rich environment with other children who were talking,

it made more of a difference to his development, whereas at home, he can fall into lazy habits, as we know what he means".

With Eddie having had just one hour of physical therapy from his usual healthcare provider over the last 12 months, Linsey explained that one of the greatest frustrations is that "there's no time frame or plan in place as to when [the health centre are] getting things in order" due to the NHS being so overwhelmed. Parents were notified by Vicky Ford - the Secretary of State for Children and Families, that therapies and medical treatments should continue for children with special educational needs and disabilities during this time, whether in a hospital, educational or home setting.

Linsey told us "This hasn't happened for a lot of parents across the country and our children are missing out on services that they should have access to". In fact, a recent study showed that around 50% of children had no access to therapy at all during the first lockdown, so to raise awareness of the difficulties that families faced during this time, Eddie has become a bit of a media star! "He was on ITV news and in local newspapers highlighting the news of the closure of his nursery and to shine a light on children not getting access for therapy" Linsey told us.

Determined to overcome such challenging obstacles, Linsey explained "I would hate this year to be a complete write off with nothing but regression, so I looked at COVID as a new opportunity to put our energy into a new therapy instead, including ABM (Anat Baniel Method), and after trying that, Eddie pulled himself into a standing position, which we had been trying for 18 months". Explaining that although these "are small milestones [for many], every milestone counts"



Eddie loves to keep moving!



for Eddie, so their main priority is to provide him with alternative therapies and equipment that he can access from home.

Linsey went on to say that the reason why she is "fundraising with Tree of Hope is because I'm trying to use different equipment and technology that I can use [at home] without the need of professional input. There are so many great technologies that can help our children and COVID made me research more - now I have a wish list for Eddie which will really make a difference to his life." Linsey is hoping to purchase a vibration board "where you can do simple exercises and get really great results that will help with building strength, balance and getting the muscles to understand different movements", a "laser light therapy which you can do at home", and a soft chamber to conduct hyperbaric oxygen therapy, all of which will give Eddie a "greater intensive block of therapy".

Having access at home also removes the stress of having to travel to specialised centres and will offer the added benefit of being able to be used long after the pandemic, supporting his continual development. Whilst these therapies and equipment come at a large cost, Linsey explains that "these can be transformational for our children".

Whilst Eddie and his family have faced many barriers this past year, Linsey reflected that "when you're getting by [with his regular therapy] you can put things on the back burner, but when things are put on pause and I really think about how I can help Eddie and it's down to me, I realised the answer is in these therapies at home".

Although the national lockdowns have been a struggle for Eddie and his family, there have also been moments of pure joy as Eddie has "bonded more with his sister" by playing in the garden together, "it was the first time he's been on a trampoline and can now even say the word 'trampoline', and he has joined in with his big sister's home schooling where they are "learning phonics - he can now say 'a', 'b', 'c' and 'd'".

**See Eddie's fundraising campaign at:**

**[www.treeofhope.org.uk/eddie-mylroi/](http://www.treeofhope.org.uk/eddie-mylroi/)**

**If you know a family who you think could benefit from our support call our team on 01892 535525**



# Our work with **SUPPORTING PAWS** animals improving & enabling lives

## & their families



Milo with Nanook

Here at Tree of Hope, we believe in partnering with likeminded organisations to help ensure families have all the necessary resources to help their children. We covered our work with Supporting Paws in 2019 and this has since gone from strength to strength!

Supporting Paws was established in 2018 after directors Charlotte and Kate felt there was a real need to service families living with autism who could benefit from having a highly trained Support Dog in the home to assist with day to day living.

Tree of Hope have been supporting Supporting Paws families since 2019, to fundraise the £8,000 needed to secure themselves a furry friend, that provide support for children who find coping in certain situations very difficult.

We caught up with Charlotte to see how everything is going. Charlotte told us: "Despite the challenges of 2020 we had a really busy year with 10 puppies starting their training and 5 dogs completing their training and starting to work as permanent assistance dogs, so we're really pleased!"

Working with our families, the progress our families make with these dogs is really profound, making the impossible seem possible as Autism can make the simplest of day to day activities a real task and can overwhelm children, which puts significant strain on family life."

On asking about the difference a Supporting Paws dog makes to a child with Autism and their family, Charlotte explained "The impact of each dog is totally unique. For some families it is that their child will happily leave the house, whilst for others there is improvement in communication and interaction and for others the dog might aid concentration and focus, giving much needed sensory input."

Since 2019, we have formed a terrific partnership with Supporting Paws and helped 20 fundraising campaigns so far. Charlotte told us, "Working with Tree of Hope has been superb for our families. The support with fundraising that they receive from Tree of Hope enables them to reach their targets quickly, some within a matter of weeks! One family we assessed and accepted for their dog at the end of November 2020 and they had reached their target by the end of December. We also have a family who were not overly confident in their

ability to fundraise and therefore opted to have a companion dog rather than an assistance dog. However, with the help of Tree of Hope, they reached their target very quickly and are now going to raise further funds so that they can have an assistance dog."

After a busy and successful 2020, we wonder what 2021 has in store for Supporting Paws! Charlotte explained, "Well! 2021 looks to be our busiest year yet with 13 families already on our waiting list to get a dog. We are looking to expand our foster carer network which will in turn enable us to work with even more families in 2021." Charlotte went on to say "Once the pandemic has ended, we look forward to working with the NHS and local schools once again where our dogs go and work with children during therapy sessions and medical appointments."

One of the Supporting Paws directors who is autistic herself and has a son with autism, is also co-writing a book with another neuro diverse parent on how to adapt your parenting style to meet the needs of an autistic child. The book will be published by Jessica Kingsley publishers and should be published in 2022!

# DECLUTTER AND DONATE

Tree of Hope facilitate collections of Books, CDs, DVDs, Games and anything else with a barcode. Donate your unwanted items today to help us continue our vital work.

## HOW TO #DECLUTTERANDDONATE

**Value your unwanted goods online  
or download the Ziffit App**

**Pack up your goods and take it to your local  
click & collect store (the App and website has a  
store locator to find your closest one) or,  
depending on the weight and contents of your  
package, a courier service may be offered**

**Ziffit will collect your goods for  
FREE! 100% of the funds will then  
be donated to Tree of Hope**



**Tree of Hope**

Transforming the health of  
sick and disabled children

[www.ziffit.com](http://www.ziffit.com)





Edward with Mum Megan and Dad John

# #HelpforEdward

Here at Tree of Hope, we're constantly learning and working with families to help them give their children the care and specialist treatment they need. In November, we started working with #HelpforEdward a national campaign led by Megan Willis, Mum to Edward, who is campaigning to not only raise £1.2 million for her son's treatment, but to also change the face of SMA for families like hers.

At just 7 weeks old on 29th October 2020, Edward was born with Type 1 SMA, turning Megan & John and their families lives upside down.

Spinal Muscular Atrophy (SMA) is a rare, genetic neuromuscular condition in which the lack of a protein called SMN causes progressive muscle wasting and weakness, leading to loss of movement, affecting a baby's ability to walk, crawl and restricting arm, hand, head and neck movement, as well as breathing and swallowing.

Devoted parents Megan and John were immersed into a world they knew nothing about and were hit only with limited and (later learnt) outdated and incredibly bleak

statistics that 95% of children with Type 1 SMA don't live beyond the age of 2. "The first days were just a living hell" Megan stated. "We didn't have enough information that we needed to be able to cope and process the disorder Edward had." Megan explained "It was like all the air went out of the room. We made the mistake of being consumed by the very limited facts that were available and we were faced with this awful grief that our son was dying as we could only think, how can Edward beat this?"

The family concluded that the amount of research was very limited and so they took it upon themselves to do the research at a greater depth. "Everything changed for us and it was

the hope we needed." Putting the Go firmly in Megan's Get up, the campaign began, and #HopeforEdward was born, aspiring to raise £1.2 million for life changing treatment Zolgensma.

"We found out about Zolgensma and it was the first real hope we had that would give Edward the best possible option, it's not something we could sit around and wait for." Thought to be the most expensive drug in the world, Zolgensma is a one-time jab that can completely halt Edward's rapid deterioration, allowing him to lead a healthy life that all parents wish for their children. Babies with SMA have a faulty or missing SMN1 gene so can't make enough SMN, which Zolgensma replaces. The corrected gene is put

into a virus (that's had its DNA removed) and is then injected into the baby's hand. Whilst the family recognise it is a huge sum of money to raise, the chance it gives Edward to thrive from just a one-time treatment is priceless.

To ensure he doesn't deteriorate in the meantime, Edward has started the widely known treatment Spinraza on the NHS. Edward's type of SMA means he can access this freely but it's a bridging solution and the effects aren't long term and it would be likely he would need to have this regularly, alongside physiotherapy for the length of his life, to keep up the effects. It's also highly invasive.

"The improvements in Edward already are just amazing, he can move his little arms and legs and he has slightly more control over his head movements. We couldn't be happier with his progress so far, but speaking to other SMA parents I've met, this most definitely isn't long term and it does wear off within a few months which is why we're going for the Zolgensma.

The money raised will also be used to help Edward's development including physiotherapy, hydrotherapy and equipment. Megan explained, "Edward needs to be pushed in every way possible to ensure he's given the best chance. We're starting physiotherapy soon at Kids Physio Works to make sure we're keeping on top of Edward's development. He will always have SMA, we just need to manage it for the time being before he gets Zolgensma, as with SMA time is of the essence."

The family set up a crowdfunding campaign, which raised over £30,000 in a matter of days. The family then partnered with Tree of Hope to benefit from the gift aid and having a registered charity attached to help further legitimise their cause and increase PR opportunities. Since then, the campaign has raised over an incredible £120,000. On asking about their initial quick success of their campaign, Megan explained, "I would say about 95% of support has come from social media. The Daily Mail article has raised about £40,000 so that really has been amazing. "Most of the money has been raised through Instagram and raising awareness and lots of people sharing our stories. My family is quite big and everyone at the very beginning put absolutely everything into spreading the word. My brother runs a business and

he just dropped everything for Edward, it's been a massive team effort." Megan went on to say "Our family and friend connections got celebrities following and sharing our posts and regular updates about Edward. You just need the right people to share with the right following. Actress Daisy Mae Cooper helped the family raise the initial £40,000.

The family's campaign exploded. Megan told us "The first couple of months of having Edward were just crazy for the whole family and it definitely burnt us out and over Christmas we needed a break and wanted to just enjoy Edward. Edward needed his Mum and not me sitting on my phone plugging away constantly."

Megan has become a huge advocate in championing SMA to help spread awareness to help ensure less families are faced with the heartache they and hundreds more get hit with every year. Megan is working with SMA charities to help campaign for an SMA Screening Programme to be implemented, which got rejected in 2018, due to there being no treatment available until 2017, meaning a lack of research to quantify improvements; but Megan sees a real opportunity for the possibility of it eradicating SMA in the future. She told us, "The programme is very new and still in it's trial stages, but with Edward it's something I completely believe should be normal and available to everyone. Oxford University are currently doing trial screenings and their research has shown that 100% of children who have Spinraza or Zolgensma treatment before symptoms show go onto live a symptom free life. Now there are effective drugs, there is hope.

We asked what advice Megan and John would give to other parents who find out their child has SMA. "Don't panic!" Megan and John both said in unison! Megan went on to say "and do your research. It really did give us massive hope and that has carried us. If Edward gets Zolgensma, the research tells us that he will live to be an adult and have a good healthy life. Look past the negativity and the stats that are no longer relevant and don't compare your child to any other."

Megan also said "I would also say enjoy your child as well. I was so focused on Edward having SMA, we thought he was dying, but that wasn't the case at all, and

you won't get that time back. I wasn't in that new-born bubble, just keep the faith and have the hope that everything will be OK. The expectation when you have a baby is that it will never be you that has a seriously ill child and we have taken the time to mourn the healthy son we wanted to have, but don't let it consume you. Yes, your life will be more difficult, and your commitments will be bigger than a 'normal' family, but your baby is your baby, so treasure that. Find the strength to be that parent you want to be because you have to get on with it." Megan and her family's background and combined experience meant that they took to crowdfunding quite naturally and a good plan and use of family's support was key. Megan told us "Since Christmas, we're all ready to hit the ground running again. We have our first Zoom meeting tonight to get a plan together. We always have meetings; we have minutes and everything!"

Megan went on to say, "I basically delegate and everyone else involved has their jobs and they do it. My sister manages Facebook, my friend manages Twitter, I have another friend who does all of our corporate support, which means I can focus on Edward.

We asked Megan what advice she would give to Tree of Hope families fundraising, to which Megan said, "Use your resources. Tree of Hope provide campaign management and good PR opportunities, that we have benefited from. With the gift aid you get for your donations as well, it's the way to go."

Follow Help for Edward on Instagram:

@helpforedward

Donate to their huge target here:

[www.justgiving.com/helpforedward](http://www.justgiving.com/helpforedward)

If you know a family that need our help, contact our Family Support team today on

[families@treeofhope.org.uk](mailto:families@treeofhope.org.uk)



# Fundraising News



## Virtual Christmas Thanks!

A big thank you to all of our contributors to our virtual christmas fundraising - this included workshops from GBBO Finalist and Tree of Hope patron Jane Beedle, Nell Price at the Arty Farty Retreat, the many stall holders who took part in our virtual christmas fair and our virtual grotto with gifts donated by Emma Blakeborough at Party Bags Online and of course Father Christmas himself. We also arranged a Silent Auction with many prizes donated by our supporters including our corporate supporters ASDA and Tesco.

This all raised just over £3000 - thank you to everyone who joined and donated!



## Valentines Week!

We are hosting two fundraising Zoom classes during the week of lurrve! Head to our Event and Campaigns page on our website to book and to get more details about what you'll need.

**Monday 8th February - 7:00pm - 8:00pm**

**Cocktail Making Masterclass with Tammy known as ForCocktailSake**

This is a real time and interactive masterclass which will be great fun. Tammy is amazingly creative and will be making Gin or Vodka based cocktails and a Whisky Sour, both with a Valentines twist!  
£10.00 per device (via Zoom)



**Thursday 11th February - 4:00pm - 5:30pm**

**Valentines Bake-a-long with GBBO Finalist Jane Beedle**

Jane's Baking Workshops have been so popular during the lockdown and we are so pleased that Jane has generously offered to support once again. Jane will be making a deliciously indulgent chocolate tart for Valentines!



## 40 Days of Hope



We are excited to launch our Lent campaign - 40 Days of Hope. Our challenge involves acts of kindness, gratitude and hope as well as the opportunity to raise much needed funds for our cause, including practical tasks to help keep you busy during lockdown.

Download your resource pack from our website:

[www.treeofhope.org.uk/resources/](http://www.treeofhope.org.uk/resources/)

And share with us your progress by tagging us on social media and using the hashtag 40daysofHope

Everyone can get involved so please encourage your friends, families and colleagues!

## Easter Holidays

We will be running a series of Easter workshops designed especially for children and young people. For full details, keep an eye on our website. These will include:

- Papercrafts
- Bake a long
- Mindfulness
- Exercise and Fitness
- Creative Making



## Save the Date!

**Sunday 27th June - Summer Fair at the Castle - Tonbridge Castle**

We are hopeful that we will be able to go ahead this year with our postponed event from 2020.

If you are a potential stall holder and would like to know more, please do get in touch with with **Karen.Warner@treeofhope.org.uk**

## Handlesbanken

A huge thank you to Handlesbanken in Tunbridge Wells who have continued to support us via sponsorship for our events in 2020, this makes such a big difference to us. Sponsorship packages are always available for all our events, so if you are looking for a corporate partnership working with a great charity, do get in touch!

**Handelsbanken**

## Volunteering



A special thanks to all of our student volunteers who continue to work with us and support our fundraising, as part of their Duke of Edinburgh awards and work experience placements. We are always open to working with students and have committed to and continue to work with them virtually until we can safely work again face to face. If you are interested and would like to get involved, please get in touch.



# Thank you to our Trust & Foundations



HM Government

In partnership with

THE NATIONAL LOTTERY  
COMMUNITY FUND



In March 2020 we launched an emergency appeal to be able to keep our services open all year and be able to offer extra support to Tree of Hope children, and support new families – and thanks to many generous and kind people and Trusts and Foundations, we were able to do exactly that.

Many of the amazing individuals and organisations who helped us will choose to remain anonymous publicly, and as much as we would like to shout about how fantastic you all are, we respect your privacy – please just know that we are incredibly grateful to each and every one of you.

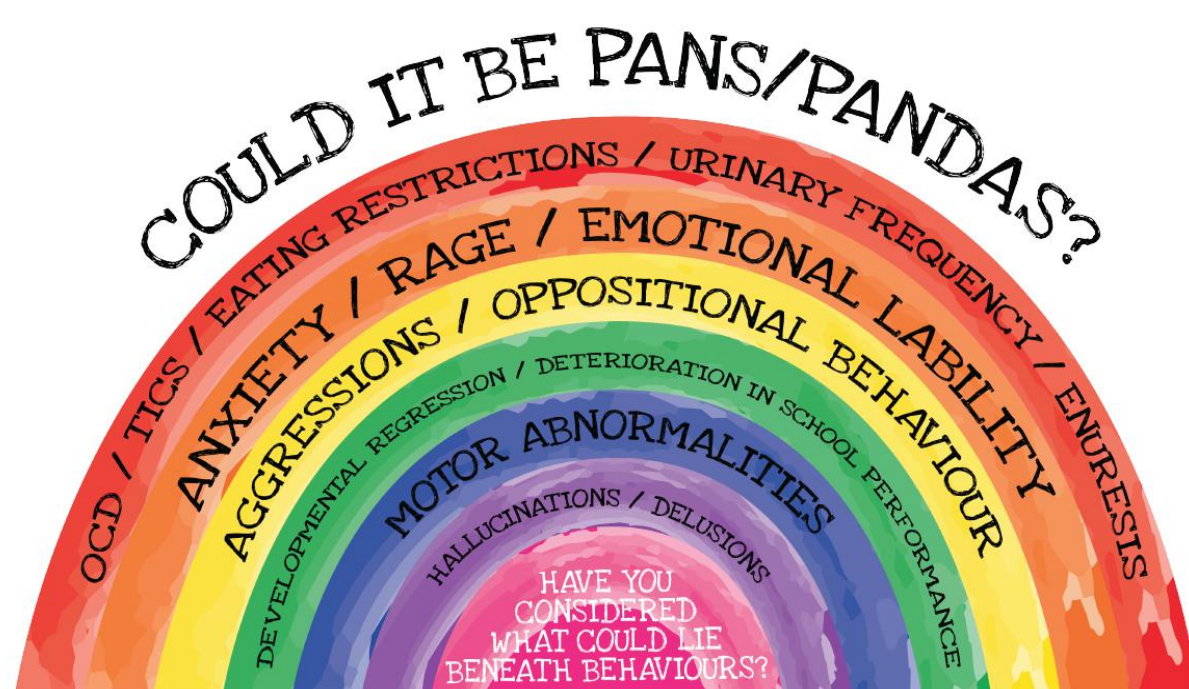
Having seen the levels of community support for and the need for Tree of Hope's services during these unprecedented circumstances, we are delighted to share that we received support from the Coronavirus Community Support Fund, distributed by the National Lottery Community Fund, which alongside the emergency appeal helped us to support the NHS by keep our services to children and their families open in 2020.

Thanks to the Government for making this possible. (We do not usually receive any government funding.)

In addition to our emergency appeal, we are delighted to share that as of October 2020, Julia and Hans Rausing are supporting Tree of Hope through their Charity Survival Fund to help ensure that our charity and it's vital work are sustainable through the winter and the beginning of 2021, as we continue to weather the storm that is Covid 19.

This is enabling hundreds of sick and disabled children and their families to continue to get the support they need with their children's healthcare and fundraising journeys during the 2nd and 3rd pandemic lockdowns, making a huge difference to many lives. Huge thanks from all of us to Julia and Hans Rausing!





**It's always very apprant to us just how many unknown conditions exist and we are always learning when we receive family enquiries. We came across PANS PANDAS a charity established by a small group of parents to help make families aware of this condition and to provide them with the support they need, as diagnosing this condition is extremely tricky. Read on to find out more!**

PANS PANDAS are experiencing more and more enquiries every day by families trying to understand why their children have suddenly changed, it is ever more important to increase recognition of these conditions.

'Paediatric Acute-onset Neuropsychiatric Syndrome' and 'Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections' are the full names of the conditions and quite a mouthful, which is why we use the acronyms PANS and PANDAS instead.

As you have no doubt seen, since the outbreak of Covid-19, there have been reports of unexpected psychiatric and neurological changes occurring in a number of those who have contracted the virus. This may sound scary, but this strange reaction to an illness is nothing new for those affected by PANS and PANDAS.

PANS and PANDAS are medical conditions which present primarily with neuro-psychiatric symptoms. Simply put, these conditions are caused by

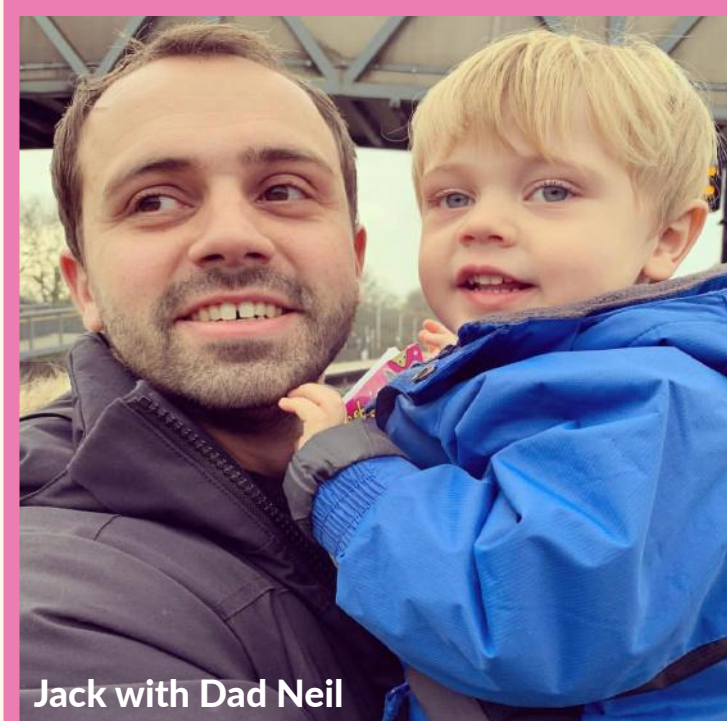
a misdirected immune response to a common infection such as strep throat or chickenpox (or even Covid-19). So, rather than just experiencing the normal symptoms of an infection, those who are susceptible can become extremely ill with a range of peculiar and seemingly unrelated symptoms overnight often losing the ability to function normally.

Many children are unable to attend school due to the severity of their symptoms and many parents have had to give up a job in order to stay home and look after their children. Awareness amongst medical professionals is poor and many children with these

conditions are either misdiagnosed with ASD, a psychiatric illness or ADHD. Indeed, in many cases children are described as extremely naughty or accused of attention seeking and



**Christopher with Dad Matt**



**Jack with Dad Neil**

parents are often blamed and sent to parenting classes. In reality, something as simple as routine antibiotic or anti-inflammatory treatments can resolve all symptoms if the condition is caught early enough. While there are no official statistics for the prevalence of these conditions in the UK, US researchers estimated that 1 in 200\* children may be affected to some degree.

It's important to stress that PANS and PANDAS are not easy conditions to diagnose as they can present so uniquely in different people. The conditions are characterised by the 'sudden onset' of obsessive-compulsive disorder, tics or eating restrictions, however, we hear frequent reports of a more gradual onset of symptoms.

As well as these key symptoms, there are a variety of co-morbid symptoms including anxiety, insomnia, bedwetting, academic regression, rage, depression and emotional lability amongst others. In many cases the presentation of these symptoms can overshadow the main symptoms, for example, whilst a child may develop OCD or tics, if they are experiencing severe rage, or hallucinations, this may be the symptom which worries the parents the most and so they may not even mention the other symptoms to their doctor. It is important to ensure that all symptoms are looked at as it is the compilation of symptoms which paint the picture, not just one or two. If you have noticed a change in your child's personality and you suspect

PANS or PANDAS may be to blame, don't delay! Visit our website for information to take to your GP. There is a great deal of misinformation regarding the conditions and so it is important to ensure the resources you use are up to date and from a reputable source.

PANS PANDAS UK was formed to educate medical professionals and support families around

the UK and the charity work closely with a network of doctors called the PANS Physicians Network. This network of doctors meet quarterly, offering training, sharing knowledge and developing understanding of these complex conditions to ensure recognition, diagnosis and treatment improves.

Meet Jack. Following recurring bouts of tonsillitis, 2 year old Jack developed severe OCD, tics and extreme anxiety. He stopped talking, stopped eating and even struggled to wear clothes as they would cause his skin pain. Jack saw many doctors who decided it was Tourette's or possibly an allergy. Jack became increasingly poorly until by chance his parents saw an interview on 'This Morning' where a mother was describing her son's illness. This mother could have been speaking about Jack! Jack's parents contacted their GP, who had never heard of the condition PANDAS forcing Jack's parents to track down the doctor who was interviewed alongside the parent on This Morning. This doctor suspected PANDAS and started Jack on antibiotics immediately. Within 2 weeks of treatment Jack was back to his lovely cheerful self and almost all symptoms had gone! Jack's dad Neil comments:

"Jack is improving every day, he still definitely has some effects of PANDAS, that we are managing well with the help of the doctor who has been amazing. There is absolutely no question that 'This Morning' and the parents who were brave enough to

go on the show and share their story, have saved our son's quality of life, we are so grateful to them.

Meet Christopher. Christopher's story started in January 2019 when he developed an infection. After various trips to the doctors over the coming weeks, Christopher's parents were told it was a virus and no treatment was necessary. They soon started seeing behavioural changes and sensory issues and it quickly became apparent that something awful was happening. Within the space of 2 weeks, Christopher had developed a body tic, verbal tics, memory issues, anxiety, OCD, became withdrawn at school and his behaviour was awful.

Christopher was changing right before his parent's eyes and they just didn't know what to do to save him. They started researching what it could be online and found the PANS PANDAS UK website. Christopher's Dad, Matt comments:

"Our son had all of the symptoms and the website stated this disorder can be brought on by a strep illness. We knew he had been unwell weeks prior to the onset of all these symptoms and that this was what had caused these problems. We immediately went back to the GP with some resources from the charity. Luckily, the GP we saw this time knew exactly what we were talking about and had trained in paediatrics. He gave us two weeks of antibiotics and blood forms to get the necessary tests done. We were also referred to an NHS paediatrician. Within 3 days of the ibuprofen and antibiotics Christopher's speech started returning to normal, his behaviour became more rational, the anxiety was better and his body tic wasn't as frequent."

\*[www.pandasnetwork.org/statistics](http://www.pandasnetwork.org/statistics)

**For more information and the diagnostic criteria for PANS PANDAS, please visit:**

**[www.panspandasuk.org](http://www.panspandasuk.org)**  
or email

**[secretary@panspandasuk.org](mailto:secretary@panspandasuk.org)**



# The importance of Specialist Equipment



Happy Arthur on his trike!



Sam enjoying the snow!

For many of the children that we support, increasing mobility and staying active is imperative to building physical strength, encouraging independence and supporting continual development.

Providing a lifeline to many children, Quest 88 and many other equipment suppliers manufacture and supply adaptable equipment such as bicycles, trikes, walkers and rehabilitation equipment, to encourage children with varying ranges of physical abilities to keep active, whilst offering a sense of freedom and the chance to challenge their mobility.

Purchasing adaptable equipment for children not only allows parents the opportunity to offer regular physical therapy in a natural environment but equally as important, children can benefit from a sense of inclusion and enjoyment from being able to participate in sporting, fitness and physical activities with their family and friends, something which they otherwise may have struggled to do.

During a year in which many therapy services have been restricted or temporarily put on hold, Quest 88's products have offered invaluable support to parents who may have struggled to provide their child with regular physical therapy. The equipment is designed with functionality and practicality at its core, so that families are easily able to continue to offer their child the opportunity to build strength and increase mobility, without the assistance of their usual therapy sessions.

One of our lovely families who fundraised for a 'RaceRunner' told us just how much their son, Sam, had benefited from the equipment, especially during the pandemic. Mum Camilla explained that "during the lockdown, we have mapped out a short route around our town for him to complete as his daily exercise – it's brilliant. It enables him to take exercise and get his

heart pumping, and it is so light and easy to push that he, who has quadriplegic cerebral palsy and spends most of his life in a wheelchair, gets a great sense of satisfaction of being able to move it".

A sense of freedom is something that another of our children has also enjoyed. Arthur recently received his trike from Quest 88, with mum, Lucy, explaining that it really has been "fantastic for Arthur, especially getting his muscles moving and to give him an added layer of freedom". He has been able to "ride through the park [on his trike] with our dog running alongside him" which is "something you often take for granted, but for children with special needs, everything takes a little bit more thought", but fundraising with Tree of Hope is something "I am so glad that we did. The charity has been a godsend as I spent all of last year worrying about how I would get this trike, so when I found Tree of Hope it all seemed too good to be true. We raised the money overnight, which was such a weight off my shoulders, and we are so grateful to the charity".

Tree of Hope values the difference that regular exercise can have on a child's physical and emotional development and is very proud to have Quest 88 as a valued supplier so that together we can continue to help families with complex healthcare needs. In partnership with Quest 88, all Tree of Hope families will receive a 10% discount on purchases for all Quest 88 products.

**Do you know a family that needs our help to fundraise?**  
**Contact our Family Support team on 01892 535525**

## Support Tree of Hope

Tree of Hope offers hope to seriously ill and disabled children living in the UK and their families by helping them to raise funds for vital operations that the NHS can't provide, therapies and treatments needed for rehabilitation and improvement, and specialist disability equipment and/or adaptations to a family home.

### We need your support to make a difference!

You can help to improve the lives of children with complex disabilities and illnesses by making a regular donation or a one-off gift to Tree of Hope.

### Your gift will enable Tree of Hope to:

- continue providing the legitimacy of belonging to a well-respected charity to hundreds of families, enabling them to access funds for their child that would not be possible otherwise
- offer online giving platforms for fundraising, making the fundraising journey far more simple for the family than it could be otherwise
- provide advice and guidance on the best ways of fundraising, and giving support throughout a family's fundraising campaign, including dealing with invoices and suppliers, and sharing news of other families in similar positions, reducing the stress for families in very difficult situations

- You can donate by cheque which needs to be made payable to 'Tree of Hope'. Cheques can be posted to our address: Tree of Hope, Salford House, 19-21 Quarry Hill Road, Tonbridge, Kent. TN9 2RN

- You can donate by paying directly into our bank account, details below:

Tree of Hope  
Metro Bank

Account Number: 21862665

Sort Code: 23-05-80

Payment Reference: TOHGDonation

- You can set up a standing order from your own bank account for a monthly donation using the above bank details
- You can donate online via [www.treeofhope.org.uk](http://www.treeofhope.org.uk) using the Donate to Tree of Hope button. We use a platform called Go Cardless which pay us via direct debit. DD are used for either a monthly or one-off donations.
- To donate by text, text 'TOHDONATE' to 70085 with the number of how much you would like to donate between 1-20. The cost of a standard rate message plus the amount donated will be debited. All donations can be gift aided.
- You can set up a donation or a fundraiser via Facebook, please visit [facebook.com/treeofhope.childrenscharity](https://facebook.com/treeofhope.childrenscharity) for details and set up.
- You can now donate by shopping on Amazon, Easyfundraising and selecting Tree of Hope on the list of available charities, this is a great way to support, just remember to click Tree of Hope

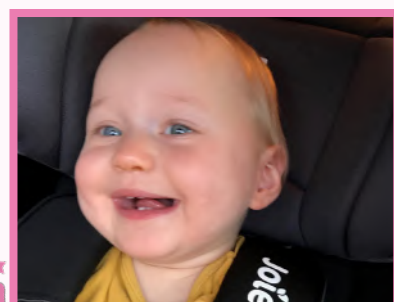
Remember to Gift Aid where applicable to add 25% to your donation at no extra cost. Please contact [accountsreceivable@treeofhope.org.uk](mailto:accountsreceivable@treeofhope.org.uk) to obtain a gift aid declaration form.

*giftaid it*





# How we help...



**Tree of Hope helps children and young people with a disability or illness by supporting their families to raise the funds that they need to pay for specialist care that is not available through the health care system.**

## Our staff team support Tree of Hope families by:

- Assisting with the creation of a Tree of Hope online fundraising campaign via Just Giving
- Making fundraising tools and advice available to parents
- Ensuring staff are available on the telephone
- Enabling each campaign to claim gift aid because it is part of registered charity Tree of Hope
- Putting families in touch with other families in similar situations for moral support
- Giving greater exposure to campaigns nationally through being associated with a well recognised charity brand
- Support with managing funds and paying invoices

## Who We Help...

- Children under the age of 18, with access to funds up to their 25th birthday
- Children anywhere within the UK
- A child suffering from a disability, illness or autism

## Medical Conditions we have helped families with (not an exhaustive list)

Cerebral Palsy  
 Retts Syndrome  
 Downs syndrome  
 Global Developmental Delay  
 Hypermobility  
 Congenital Hypotonia  
 Epilepsy  
 Visual Impairments  
 Meningitis complications  
 Lebers Congenital Amaurosis  
 Dravet Syndrome  
 Hypoxic Ischemic Encephalopathy Injury  
 Dystonia

## What you can fundraise for

Equipment including but not limited to trikes, hydrotherapy pools, specialist pushchairs & sensory equipment

Therapy, including; physiotherapy, horse riding & swimming lessons

Operations and treatment inside and outside of the UK

House Adaptations including sensory gardens and bathroom adaptations

Please remember to include all your fundraising needs at the start of your campaign. Speak to our Family Support Team on 01892 535525 for advice.



**Tree of Hope**

*Transforming the health of sick and disabled children*

**[www.treeofhope.org.uk](http://www.treeofhope.org.uk)  
 01892 535525**