



Tree of Hope

*Transforming the health of
sick and disabled children*

FEBRUARY 2023
newsletter

Inside this issue

Our 30th Year

Challenge Yourself!

Zion Turner-Geohagbon

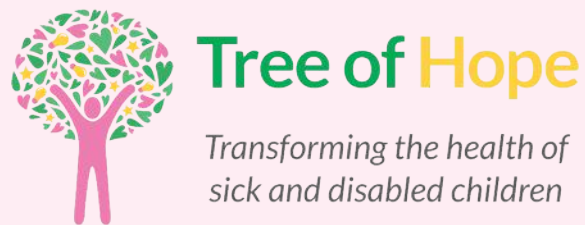
**OUR SMA
SPECIAL**



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**FUNDRAISING
REGULATOR**

Tel: 01892 535525
www.treeofhope.org.uk

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As the days are starting to lengthen and the nights are beginning to get shorter, we can start thinking of Spring and warmer days to come- well, we are ever optimistic at Tree of Hope and while we can never rule out snow as late as April, we know it's all about planning for future events and fundraisers now so that we can maximise the lovely days when they arrive.

So, remember, it is never too early to get your plans in place and to encourage others to join you and raise vital funds for your campaign. From Easter Egg Hunts to a Coronation Party do think about taking advantage of the 5 bank holiday days in April and May - yes 5 in just 2 months so lots of opportunities to plan for fun and fundraising too.

If you need some ideas or even just someone to listen, do call us, we are happy to chat and help whenever we can. Our small team now has a well-established full-time team member dedicated to Scotland/the North of England to complement our existing team members and all of us will support families and suppliers across the UK - so do call us for a chat. We are brimming with ideas to help to make a life-changing difference to your child.

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 we would love to hear from you.

Kind regards,

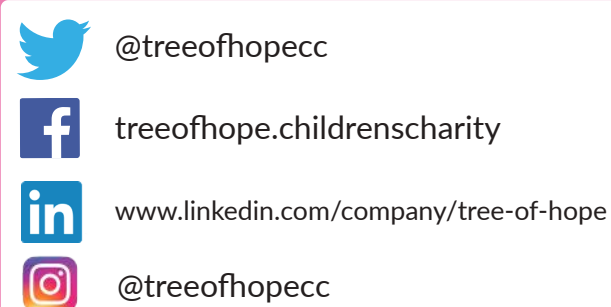
Gill

Gill Gibb
CEO



in this issue

- 3 **Hello!**
Welcome! Become a Friend of Tree of Hope!
- 4 **Zion Turner-Geohagbon**
Read about little Zion's fundraising mission
- 6 **Fundraising News**
Updates and News
- 7 **Wheelfreedom**
Our new partnership with Wheelfreedom
- 8 **30th Anniversary & Impact Report**
Find out about our momentous year
- 10 **Spinal Muscular Atrophy & our Children**
Sebastian and Sidney's SMA journeys
- 14 **Ultra Challenges!**
Take on an Ultra Challenge in 2023!
- 15 **Supporting Tree of Hope**
How you can help
- 16 **How We Help**
Disabilities and conditions we support



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HELLO



February already?! Time really does fly doesn't it, but however quickly the months roll by, we hope that your year has got off to a fantastic start.

If things do feel a bit tricky at the moment, please make sure that you reach out to us. Whether you need a hand with raising money, would like to get your campaign featured in the local news, or maybe you just want a chat, please feel free to pick up the phone. We're always up for a good natter and would love to hear from you!

For the team at Tree of Hope,

we are already in the full swing of planning another mighty year following a momentous year for the charity following our 30th anniversary celebrations.

We have a full itinerary of events and exhibitions that we will be visiting throughout the year, so keep an eye out on our website and on our socials for more information about events near you that we will be attending!

We'll be extending our support and raising awareness of Tree of Hope this year by bringing you a brand-new website which

we're so excited about! We'd really like to hear your thoughts on what you'd like to see on our new website, and things that could be improved on our current site, so please email marketing@treeofhope.org.uk with your thoughts!

As ever, we're here to help in whatever way we can, so keep in touch with us throughout your fundraising journey and beyond. Best wishes for the year ahead!

Steph, Editor

BECOME A FRIEND OF TREE OF HOPE!

We have a really wonderful relationship with so many of our loyal supporters, and so we'd really love to get to know more and more people who share our vision of helping to support as many sick and disabled children across the UK as we possibly can.

Did you know that there are currently over 1 million children registered as disabled in the UK, but there is also a

funding gap of £2.1 billion in disabled children's services? This often means that children are left waiting for vital services, receive the bare minimum of help, or are not eligible for certain avenues of support, resulting in a lack of independence, less opportunities than their able bodied peers, additional pain or emotional trauma, to name a few.

By becoming a Friend of Tree of Hope, you can help to bridge this funding gap, and ensure that more children can receive the treatment, equipment, therapies or operations and allow them to thrive. Help us to increase our reach, and help more families' hopes become a reality for their child.



By Becoming a Friend of Tree of Hope for £10 a month or £100 a year, you will receive:

- ★ Monthly updates about families and how your funds help
- ★ Annual Thank You letter from the Chairman & Impact Report
- ★ Invitations to networking events
- ★ Tree of Hope bear
- ★ Tree of Hope trolley tag
- ★ Tree of Hope rollerball pen

There are several ways to become a Tree of Hope Friend; bank transfer, cheque, standing order or online donation. To pay online, please email Karen.Warner@treeofhope.org.uk



Cheeky little Zion at home!

Zion Turner-Geohaghon

This month we're raising awareness of Rare Disease Day and Feeding Tube Awareness week. We have covered our work in the past with No Tube, a feeding clinic in Austria but we're really pleased to help raise awareness again with another of our wonderful families

Meet Zion! Zion is 2 years old and lives in Birmingham with his Mum Shanell and is a big fan of singing, especially 'Wheels on the Bus'! Zion was born prematurely and contracted Necrotizing Enterocolitis (NEC) which resulted in considerable damage to his small intestine and was later diagnosed with short gut syndrome and means at the moment, he can't absorb enough nutrients.

Zion spent the first 13 months in hospital as a baby and underwent 7 bowel surgeries where parts of his intestine were removed to help enlarge his gut to help him process more nutrition. This means that Zion is very

susceptible to things like diarrhoea as it is the large gut that is responsible to absorb the extra fluid.

Mum Shanell is determined to get Zion to a stage where he can maintain his nutrition himself. She told us "it would open so many options by having a diet so he can put on weight...he's been through a lot but is one of the lucky ones and continues to surprise his consultants. His gut and bowel are adapting really well."

Zion, for a time, was having a combination of TPN (Total Parenteral Nutrition) and tube feed. The TPN ensured he got the supply of daily

nutrition directly into the blood stream whilst he built up a nutritional tolerance with the support of tube feed to his stomach. Shanell explained that at this time getting the balance right was extremely difficult as it caused lots of hospital admissions. "We fought to get him off TPN which he's done really well at but we are now stuck in the trap of relying on tube feeding."

We asked Shanell about the realities of managing Zion's condition and how this impacts on daily life. She told us "Day to day it can be quite difficult - sometimes we just don't know how he's going to react, and monitoring his

calories and fluid are important. If he has dips in those things, it could lead to a hospital admission where he would be put on an IV drip to get the nutrition he needs." Shanell explained "his gut can only process so much" and this can really impact his bowel movements which can then have quite a negative impact on Zion's overall health in maintaining his nutrition and weight.

On asking Shanell about No Tube and where she heard about this solution, she told us "It was actually years ago, I watched a documentary about a little girl who didn't eat, and it just stuck with me. I remembered it when all this was happening, so I googled the centre to see if it was still there and contacted them." Shanell went on to say "I always thought it was really interesting and they have been great so far. They respond to emails quite quickly and they hold seminars quite often so if I'm free, I often jump on to learn about it all which is really useful."

Shanell and Zion have a good relationship with Zion's UK consultant. Shanell explained "Their main concern is his weight, when Zion came off TPN, it was essential that he was able to



Zion receiving a Rose!

maintain weight and put weight on, so it's very much the same with exploring No Tube, which is the idea."

On asking Shanell what they get up to, she told us "I do lots of activities with Zion. We go to the library, and we also go to soft play with my Mum which he loves." Shanell explained "part of the

reason Zion has an aversion to food is because of his surgeries so I try and do as much stuff with him as possible to get him more confident and used to different things." She explained "I'm always trying to think of ways to get him out and doing stuff for his development" Zion sees a physiotherapist twice a month to help his development, though

Shanell explained that "two sessions just isn't enough, so I started to take him to soft play quite a lot as I knew that would be a good place for him to gain confidence."

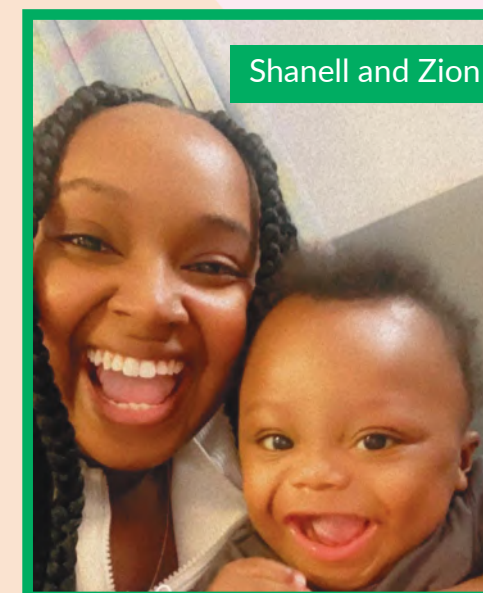
Shanell also attends a playgroup which is for parents with children who have a mix of disabilities, conditions and learning disabilities. Shanell told us "it's nice meeting other parents and hearing their stories and it's just a nice environment for Zion to mix with kids who are similar to him but also have other conditions. It's nice that they just get it," she said.

On asking Shanell what she ultimately wants to achieve for Zion, she told us "ultimately, I want to achieve him eating, even if it's just in the day, it would help him socially and his development. I want him to have a better quality of life; it would really mean a lot to us."

Shanell is off to a great start with her fundraising for Zion and explained how it makes a difference having the Tree of Hope to help fundraise as well as raising awareness. She told us "it's been really good for ideas, like reaching out to corporates for support and just helping develop what I'm doing. It never feels like it's just me on my own." She went on to say "fundraising with Gofundme seems very independent and I can see that it would be quite easy to lose momentum and support, but the regular emails Tree of Hope send every week really help and make me think about other events and things I can do."

Shanell is organising a children's soft play fundraising party, her Dad is looking to take on a cycle challenge in the spring, as well as getting other

family members involved to support too. Shanell's cousin is Muslim and is looking to explore the support her mosque may be willing to give. Did you know that giving to charity known as 'Zakat' is one of the five pillars of Islamic religion? As a charity, Tree of



Shanell and Zion

Hope are passionate about making the brand accessible to all backgrounds and cultures. As giving is a big part of religions, including Islam, we're always really pleased that families can explore fundraising in a variety of different ways and increase awareness of their stories and extend this to other groups and communities as well.

We asked Shanell what advice she would give to a parent who is thinking about fundraising with Tree of Hope? "I would tell them to speak to you guys and just go for it! It's a bit of a scary jump because prior to this I didn't really share anything about Zion's condition, but it's enabled me to be much more open and raise awareness. Since starting I've had lots of questions and all the feedback has been really positive."

You can make a donation here!



See Zion's journey here:
www.treeofhope.org.uk/zion-turner-geohaghon/

Fundraising News

Thank you!

Tunbridge Wells Garden Centre (Blue Diamond) have supported us for several years now with collection pots. This year they have raised over **£100** from 2 collection pots at their checkouts.

Infinity Group in Tunbridge Wells who took part in the Bewl Water Dragon Boat raising **£2000** for Tree of Hope. Huge thanks to everyone who took part in the day, we hope it was fun!

Flo Paton who held a toy and cake stall in January supporting Tree of Hope. Flo raised an amazing £200, what an inspirational thing to do – and the cakes and biscuits look yummy too!

The Channel Co hosted their second awards ceremony this year in aid of Tree of Hope, the first one supporting our family campaigns directly. In November, they hosted the final event of the year supporting Tree of Hope's work directly. From their silent auction they have been able to donate over **£8000**, which is awesome! Thank you so much for your generosity!



Carols at Christmas

In December we hosted our very first Carols at Christmas event at Tonbridge School. It was a magical day and included a VIP Reception for our sponsors, trusts, major donors and significant supporters over the last few years.

Bishop Rose Hudson-Wilkin was our guest speaker and delivered a heart warming and moving tribute to Tree of Hope. We had readings from our Patrol Jane Beedle, Sponsor Nick Green from Handelsbanken, Cllr James Lark Deputy Mayor of Tonbridge and Malling Borough Council and one of our Tree of Hope parents, Nick McDonald.

The music was amazing, huge thanks to Tonbridge School's Teacher of Music and organist David Williams, who was so supportive, and of course our musicians and singers, Orpheus String Quartet, Tonbridge Community Singers, Bridget Bentall and Arianna Rebecca Firth.

We would like to say a special thank you to our Sponsors – Pure Nails (Headline Sponsors), Handelsbanken Tunbridge Wells and S & S Distribution.

We are looking forward to another event this year – so watch this space for more information later in the year.



Save the date!

Charity Golf Day at Hever Castle Golf Club on Thursday 4th May

Ride London - 28th May. If you are interested in taking part, please get in touch on challengeevents@treeofhope.org.uk

Tree of Hope's Summer Fair at Tonbridge Castle Lawn and River Walk Saturday 17th June

Charity Golf Day at Westerham Golf Club on Tuesday 19th September

www.treeofhope.org.uk/get-involved/upcoming-events/



Partnering with some of the UK's leading companies, Tree of Hope make it our mission to inform our wonderful families of organisations who may be able to help with their child's medical needs.



Paediatric showroom at Wheelfreedom

Based in Chessington, Surrey, Wheelfreedom have been providing their customers with high quality, specialist mobility equipment for over 14 years, with products ranging from manual wheelchairs, supportive buggies and powerchairs. Their product range, which is available for hire as well as purchase, feature a large selection of reputable brands, and cater to all ages. Their mobility solutions can start with your child's first wheelchair, through to teenage products and equipment that will prepare your child for adulthood.

Last year, we partnered with Wheelfreedom, who share our vision in ensuring that all children are provided with the equipment that they need to thrive in life. Within their flagship showroom, Wheelfreedom are proud of their paediatric offering, which are regularly tried and tested products from across the market. We spoke with Paediatric Consultant Craig Adams from Wheelfreedom to get an insight into their products and the service that they offer.

Craig explains that Wheelfreedom "have a broad range of products from different manufacturers" with staff

who "have the precise knowledge and are there to assess each child and their specific needs". Explaining that "our staff don't work on commission, parents can come to us with full confidence that the advice that they receive will be impartial."

As mobility equipment is not something you can just buy off the shelf, Craig tells us that one of the many benefits of purchasing equipment with Wheelfreedom, is that children and their families "have to come to our showroom to pick the right product for them with advice from experienced assessors. We don't sell directly online as we need to ensure that the product is tailored to the child. Whether this is by conducting specialist pressure mapping to help with seating, or even suiting the child's desires with personal touches like adding things like little monsters to their chair!" Craig also added that some wheelchair assessments can be done via home visits, but it would be advised for families to check out their

online interactive showroom, so that they have an idea of the products that they would like!

Of course, with Paediatric products, there needs to be consideration into the child's continuous growth, so Wheelfreedom can guarantee that "if you need something adjusting, we have an in house servicing, maintenance and repair team available in the showroom", meaning that families can rest assured that if there are ever any issues with their wheelchair, or if an adjustment is needed due to growth or additional needs, they can pop to the showroom and know that Wheelfreedom's aftercare services will be available to them.

Craig was proud of the service that Wheelfreedom can offer to families and their children, with each person's individual needs being at the forefront of their choice. Each choice is different and should be celebrated and Wheelfreedom pride themselves in their assessment facilities, range of products, their aftercare offerings, and the provision times for children's mobility equipment.

For more information please visit their website here: www.wheelfreedom.com

To browse their product range, please take a look at their interactive showroom: www.wheelfreedom.com/showroom

To be put in touch directly with Paediatric specialist, Craig, please contact info@treeofhope.org.uk and we will share all of his contact details!

Our 30th Anniversary and Impact Report!



At Tree of Hope, we work tirelessly to maximise our services to our current fundraising families, but we also look for ways in which we can grow, develop and reach more and more families who might need our help. Luckily for us, last year was our 30th Anniversary and we recieved some incredible support from our loyal supporters which made it possible for us to expand our services. Read on to find out about our 30th birthday celebrations and the impact this has had!

Over the last 30 years, we really have grown from humble beginnings and are now, proudly on a journey of growth with a mission to support as many seriously ill and disabled children across the UK. A recent study conducted in Summer 2022 by Scope and the Disabled Children's Partnership shows that there is currently a funding gap of £2.1 billion across children's healthcare, and so Tree of Hope aims to bridge this gap by helping families access what they need to help their children thrive.

Tree of Hope now support over 500 families with their fundraising campaigns and expenditures, providing support to families and empowering them to access the specialist care that their child needs.

Our growth over the years has undeniably been attributed to the wonderful support that we have seen from our incredible donors, corporate supporters, volunteers, trusts and foundations, and the general public, who truly understand the lifechanging impact that our work can have on children across the UK.

Our increased Family Support

Many of our families will now be familiar with the lovely Katie, our latest Family Support Officer, who is based in the North of England. It is with huge thanks to the Rooney Foundation that we were able to recruit Katie back in March, and she has been an incredible addition to the team. Not only has Katie met up with some of our families in the North to offer increased face-to-face support, she has also been able to travel to events further afield, including Scotland, for the first time! Awareness of our services is key to our growth,

to reach as many families as we can, with so many in need of help.

On the road again

Having Katie on the team has also meant that we have been able to have more representation at exhibitions across the UK. For the first time since the pandemic, Tree of Hope have been able to get out and about to in-person events, from the Kidz to Adultz Exhibitions to Family Fund Information Days. We've been able to catch up with some of our long-term suppliers, meet new organisations and form new partnerships, and of course, meet some inspirational children and their families.

Events such as these offer families a unique experience to browse through a huge variety of state-of-the-art equipment of different makes and models, which could have a life-changing impact for children and their families. However, we also understand how overwhelming the day can be for parents who leave with a huge shopping list of equipment that they need to fund for themselves.

At each event that we have attended, we've been so pleased to be there to support families who might need a funding solution; we can explain all of the benefits of fundraising with a registered charity! This year we'll be attending more events, so keep an eye on our events page on our website to find out where we will be and when. Not only do we love a good natter, but we also come fully kitted with goodies for you to take home, including some new merchandise for 2023!

Celebrating Tree of Hope

The growth of Tree of Hope has enabled these positive changes over the past year, and so not only have we wanted to share our achievements with our wonderful supporters, old and new, but we have, this year, really aimed to maximise our general fundraising events to enable us to continue to be able to grow, and ultimately reach more and more people who need our help. Increasing



The team at Kidz to Adultz

our presence within Tonbridge and Tunbridge Wells, where we are based, we have held both a Summer Fair and Carols at Christmas event to increase brand awareness and raise more vital funds to support our growth.

The Summer Fair at Tonbridge Castle was our first in-person event since the pandemic and was received really well by our guests. We were joined by a lovely selection of local businesses, some of which have supported us for a while, and others who are new supporters of ours.

We were also joined by local radio station KMFM who helped to sell raffle tickets. Everyone who came had a brilliant day! We're looking forward to our now flagship event, Tree of Hope's second Summer Fair later this year. Take a look at page 6 for more information!

Our 30th anniversary celebrations culminated in our Carols at Christmas event at Tonbridge School on Wednesday 21st December, a truly magical event for us and all of our guests. We had some wonderful performances of well-loved carols and a Christmas message delivered by the Bishop of Dover who beautifully

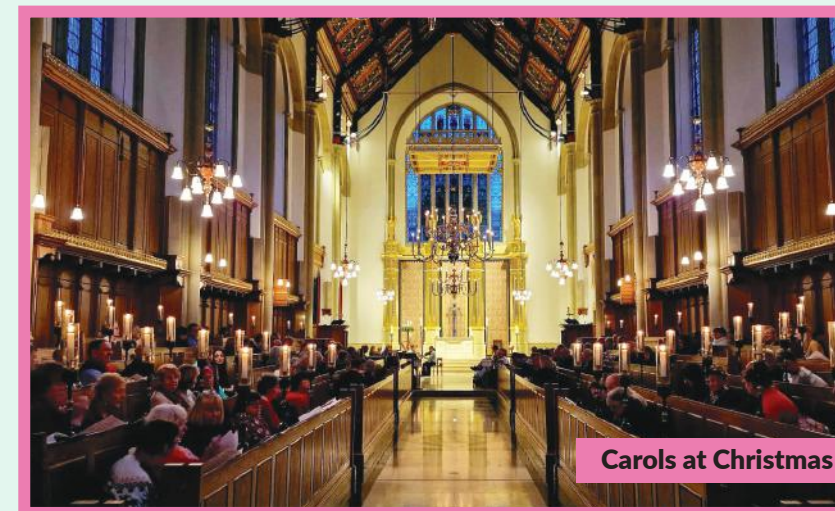
captured the essence of Tree of Hope and charity giving during her sermon. Following the service in St Augustine's Chapel, a stunning candle-lit setting, our guests joined us for drinks and mince pies, and we were lucky enough to meet one of our families who attended the event, as well as our incredible local (and not so local) supporters from a range of trusts, foundations and organisations. It was the perfect ending to a very special year for us.

Our Impact

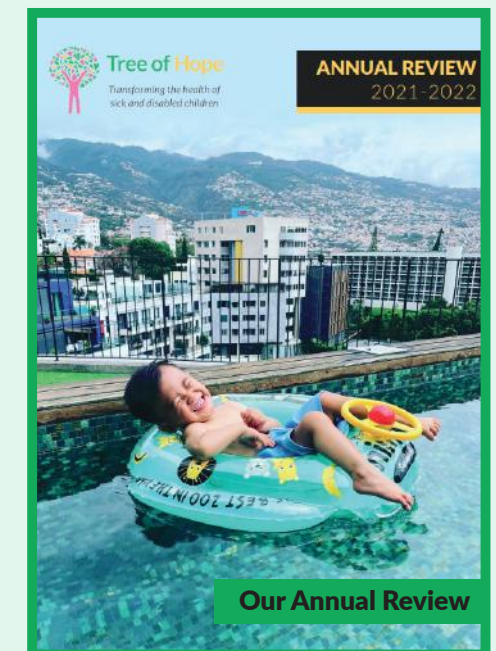
At the heart of all of our work is our families – we do what we do to make their lives easier and to help

provide their children with the care that they need. Of course, we know that it's been another challenging year due to the cost of living crisis, but our amazing families have shown such resilience. We continue to help families all over the UK and look forward to meeting and talking to many more lovely families over the next year and beyond!

Tree of Hope have been able to change lives with the below expenditure:



Carols at Christmas



Our Annual Review

c£197,000

was spent on the additional family living expenses

c£24,000

was used to support Autism Therapies

c£202,000

bought over 160 pieces of specialist equipment

c£392,000

was spent on specialist therapies

c£21,000

was used for Autism Assistance Dogs

c£558,000

was spent on operations

c£42,000

was used to support home adaptations

Download our 2021-2022 Annual Review here!



SCAN ME

Spinal Muscular Atrophy & our families



Every five days in the UK, a baby is born with Spinal Muscular Atrophy (SMA), and over the last few years, Tree of Hope have heard from more and more families whose children have been diagnosed with the condition. With the ever-growing advancement of modern medicine, the outlook for children with the condition is brighter than ever before, particularly with the help and support of specialist mobility equipment and physiotherapy to aid the child's development as they grow. We've been delighted to support some wonderful children and their families as they navigate through the challenges that SMA can bring, so please read on to find out more.

What is SMA?

Spinal Muscular Atrophy (SMA) is a rare, genetic, neuromuscular condition. It causes progressive muscle weakness and loss of movement due to muscle wasting (atrophy). This may affect crawling and walking ability, arm, hand, head and neck movement, breathing and swallowing. There are different forms of SMA and a wide spectrum of how severely children and adults are affected.

How can SMA be treated?

SMA has recently been hitting the headlines due to some exciting developments in treatments compared to six years ago when there was no treatment for SMA in the UK. In March 2021, the NHS agreed to provide Zolgensma given as a single intravenous infusion to children with the severest and most common type, SMA Type 1, who meet the eligibility criteria

Previously, without treatment, babies born with SMA Type 1 had a life expectancy of just two years. In studies these treatments have helped many of these babies reach milestones such as breathing without a ventilator, sitting up on their own and crawling and walking.

Miraculous though this is, the Zolgensma treatment is just the

beginning of the treatment journey. Without the correct aftercare, the treatment has been likened to going into battle with the best machine gun but with no bullets, and as much as possible must be done to increase the child's strength, which is why physiotherapy, hydrotherapy and other therapies are so important.

Tree of Hope currently supports five families whose children have been diagnosed with SMA and we recently caught up with a couple of them to chat about how they managed the ups and downs of a diagnosis of SMA.

First up, Sidney!

Born in April 2021, Sidney is a cheeky



Cheeky Sidney



Sidney in Physio

little chappy who lives at home with his parents, Sophie and Aden, and big sister Nancy. Sidney loves to go to the baby and toddler playgroup with his friends in his wheelchair. He also loves water and enjoys his swimming lessons. He is very into his animals and loves making different animal noises too!

At four months old, Sophie was realising something wasn't quite right and having googled Sidney's symptoms suspected that he might have SMA. Sid was later diagnosed with type 1 SMA which makes day to day life challenging for the whole family. Sidney was given Zolgensma at four and a half months old but the condition has affected his muscles throughout his body, and therefore impacts his movement all over, his breathing and his swallowing.

He sleeps with a ventilator at night, so his parents are constantly on high alert listening out for his alarms to make sure he is safe. Sidney is unable to sit, weight bear and his condition has left him physically disabled. Mum, Sophie told us "Sidney's diagnosis

has turned our world upside down. We have multiple appointments to attend for him each week which can be hard going, as it really impacts your quality of life. As he is growing older, we are realising the impact his condition will have on his future, and all the small things we take for granted, such as accessibility and joining in like other children his age. Lifting him is becoming increasingly difficult as he grows, Sidney's muscle weakness means that his body is really floppy so when we carry him, it's very difficult."

Sidney's condition has also had a big effect on his sister Nancy. Sophie explained "She does so much to try and help out with Sidney, she's always looking out for him and I'm so proud of her. I worry a lot about the impact this last 18 months have had on her and whilst we try hard to make things as normal as possible, she has endured so much, more than any four year old should have to".

Sidney's family are fundraising with Tree of Hope for

physiotherapy and hydrotherapy sessions which are helping to build his muscles, as well as vital house adaptations as these aren't covered by the council DFG. The cost of this needs to be paid for privately which is costly, especially now that Sophie can not return to work due to Sidney's care needs.

The family also fly every four months to Barcelona for Sid to receive a drug as part of a clinical trial which he has really seen benefit from, but the trips are not fully covered by the drug company so the costs mount up! Exciting plans are afoot to travel to other countries to see specialists and rehabilitation centres.

The family are already seeing progress with Sidney's strength from all the hard work he is doing with his physiotherapist and are very hopeful that he will go from strength to strength. Already, Sidney has gained the ability to sit up and has also started to do some standing with the help of orthotics, so they know it is paying off. "The main aim is to get Sidney as strong as possible so that we are able to give him the life he deserves. Working with our private physio has been amazing – they genuinely care about our kids and trying to help them."

The family have recently begun working with Tree of Hope to fundraise for Sidney's needs. On asking Sophie about the support Tree of Hope have provided so far she explained that "The great thing about Tree of Hope is that anyone who donates have the reassurance that all the money is spent directly on the child, so it takes away the stress of worrying about what

" The main aim is to get Sidney as strong as possible so that we are able to give him the life he deserves. "



Sidney and sister, Nancy

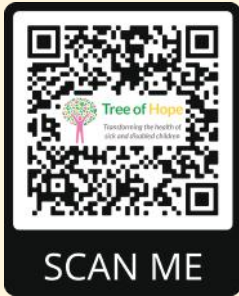
people think of your fundraising. It's just a more official platform so that people know that the money is being spent correctly."

You can keep up to date with Sidney's fundraising page by visiting his Tree of Hope webpage here:

www.treeofhope.org.uk/help-super-sid-fight-sma-type-1/

Or follow his Instagram: @Super_Sidney_Cookie

You can make a donation here!



Meet Sebastian!
Sebastian is a chirpy little boy who brings his parents Dharmisha and Jakub so much joy. He loves exploring, checking out the swings and slides in his local playground and is showing an early flair for cooking by helping out with meal preparation whenever he can!

Dharmisha and Jakub began to suspect something was wrong after noticing that Sebastian was not hitting the same milestones as his peers. Sebastian was diagnosed SMA Type 1 in June 2021. Fortunately for the family, Zolgensma had just been approved in the UK, although it was still a difficult decision to make.

Jakub explained that "After several phone calls and emails and generally making as much

noise as possible, Sebastian was invited to the Evelina hospital for vigorous testing to ensure he was well enough to receive the drug and after the constant nail-biting between tests and results, Sebastian was given the all clear. He would receive Zolgensma the following week. On the 30th June 2021 we had to listen to a doctor tell us all the risks that come with Zolgensma. Liver failure, heart failure, low platelets amongst other things, including that this might not work. We appreciate that this was all routine, but nothing in our lives could have prepared us for this reality. And we didn't have any choice, this was Sebastian's best shot at gaining movement and more importantly staying alive."

Sebastian's diagnosis changed everything his parents had planned for his early years. Jakub explained that "the hypertonia he has been left with can be compared to a toddler trying to move with a 10 kilogram sack of potatoes on their back, so the scale of the challenge he faces is enormous. However, he is so bright and joyous and really enjoys life. We now try not to have

expectations as to his development but take things as they come and celebrate the little things such as him learning to eat with a spoon".

Rather than giving birthday gifts the family have asked their friends and family to donate to Sebastian's campaign. The funds go towards regular physiotherapy and hydrotherapy sessions which Sebastian requires bi-weekly.

" We now try not to have expectations as to his development but take things as they come and celebrate the little things "

The family have also decided to fund his RSV (Respiratory syncytial virus) immunisation at a total cost of £7800. Usually a mild infection, for SMA children RSV can be very serious and result in a hospital stay. When a bigger

expenditure such as house adaptations are needed the family will broaden their fundraising efforts but currently this approach is working well for them.

Jakub said that fundraising with Tree of Hope has been a very positive experience. "The process is straightforward and gives certainty to donors that the money is going to the



Sebastian & his parents



Sebastian keeping warm!

child. They also provide a lot of ideas and support for our fundraising."

You can keep up to date with Sebastian's fundraising page by visiting his Tree of Hope webpage here:

www.treeofhope.org.uk/help-for-sebastian/

Or follow him on Instagram: @dharm_sebastiansmum

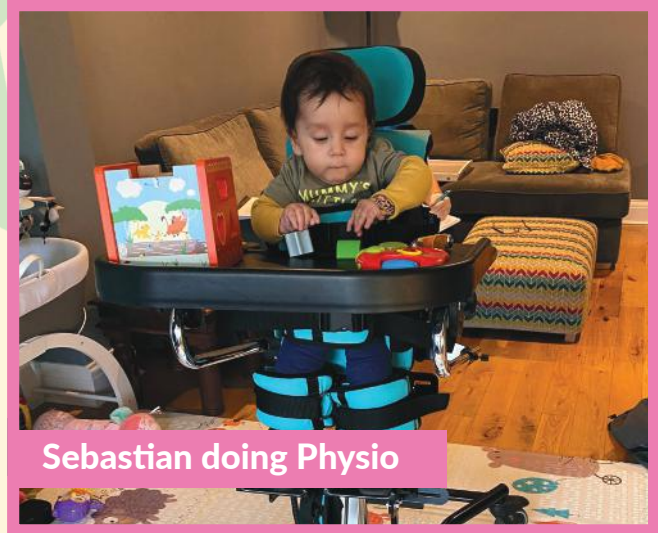
You can make a donation here!



Hope for SMA families
It's really amazing for us to hear about the positive developments that both Sebastian and Sidney have

found from attending regular therapy sessions, provided by some brilliant organisations who work together to ensure that the children are given all the tools needed to thrive.

The future looks bright for children with SMA, particularly with the advocacy of the earliest possible introduction of newborn screening for Spinal Muscular Atrophy. There is clear evidence to support the idea that early diagnosis and treatment for SMA (often pre-symptomatically) leads to the best possible outcomes for the child and reduces future healthcare needs.



Sebastian doing Physio

TREE OF HOPE SMA RESEARCH
To ensure that we can support our families who have a child with an SMA diagnosis and to develop our understanding of the condition, we are conducting a research project investigating the impacts that SMA treatments have on both the children and their families.

This research is being led by our Placement Research Support Officer, Charlotte Pugh from the University of Kent and to give a greater insight into family perspective after treatments, how they benefit children and families and taking diagnoses, treatment and lifestyles into account as well.



Introducing Charlotte!

Participation is completely voluntary! We are looking to give families support in their journeys and give them a voice to share their experiences as this is something that has only briefly been explored.

If you or anyone you know would be interested in volunteering to contribute to our study we would love to hear from you! Please email: charlotte.pugh@treeofhope.org.uk

We've partnered with The Ultra Challenge Series!



This year, Tree of Hope are partnered with the Ultra Challenge Series! Each year, the Ultra Challenge Series puts on a variety of epic events throughout the UK, and we wanted to get a slice of the action and allow our brilliant supporters the chance to raise funds for Tree of Hope in style!

Throughout 2023, there are a total of 14 challenges taking place to suit the ultra-experts as well as the beginners, so there really is something to suit anyone who wants to achieve something special! Starting at 10km challenges all the way through to 100km adventures, you really can pick whatever you want – whether that be a coastline trail or an inner city challenge.

We are really pleased to be able to offer spaces to our wonderful supporters, and we'd absolutely love for you to get in touch if you're a walker, jogger, or runner

looking for a challenge. When you sign up, we will get in touch to discuss the event that you want to take on. We will send you a fundraising pack and we will provide full support, social media promotion and any PR support to help you with your fundraising if this is something that you'd like to do!

Take a look at what's on offer below, find out more about each event, and register your place by getting in touch with us! Please email info@treeofhope.org.uk



- | | |
|---|--|
| 1 Winter Walk - 28th & 29th Jan | 8 Peak District Challenge - 8/9 July |
| 2 Easter 50 Challenge - 1st April | 9 North Downs 50 Challenge - 22 nd July |
| 3 Isle of Wight Challenge - 29/30 April | 10 South West Coast 50 - 5 th August |
| 4 Jurassic Coast Challenge - 13/14 May | 11 South Coast Challenge - 2/3 September |
| 5 London 2 Brighton - 27/28 May | 12 Thames Bridges Trek - 9 th September |
| 6 Lake District Challenge - 10/11 June | 13 Thames Path - 9/10 September |
| 7 Cotswold Way Challenge - 24/25 June | 14 Chiltern 50 - 23 September |

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, 61-63 Camden Road, Tunbridge Wells, Kent, TN1 2QE

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

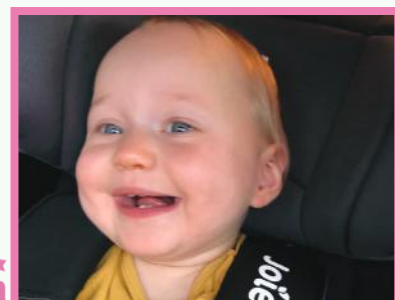
Tree of Hope
Metro Bank
Account Number: 21862665
Sort Code: 23-05-80
Payment Reference: TOHGDonation

- 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 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 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 every time you shop.

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

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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

**www.treeofhope.org.uk
01892 535525**

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