

## Inside

⊙ Kenny's new normal Our exciting plans for the future  ${ig>}$  Children sing with Elaine Paige



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# Welcome to inspire

Thank you so much for your amazing fundraising efforts and continued support. It is especially welcome right now as the pandemic continues to affect our usual fundraising.

The risk of Covid-19 is still very real for the children too and keeping them safe is our priority – children are still shielding and we have separate 'bubbles' for children in the houses on-site. We're sourcing PPE, investing in IT and more education for our staff, so we're in a great position to carry on doing what we do best.

Despite everything, we haven't stopped planning for the future. In April, we launched an exciting new strategy called 'Hope and Ambition'. It sets out how we aim to help every child with an acquired brain injury. We're delighted to share our innovative plans with you in this issue.

Our Brain Injury Community Service (BICS) team tell us how they continued to support



Dalton Leong, Chief Executive and Duncan Ingram, Chair of Trustees proudly launched our Strategy for 2020-2025: Hope and Ambition in April 2020.

The Children's Trust, Tadworth Court, Tadworth, Surrey KT20 5RU

01737 364 349

thechildrenstrust.org.uk



Registered with FUNDRAISING **REGULATOR**  children and families in their communities during lockdown too, turning their usual home visits into virtual visits.

Our work must not stop. And your amazing support is helping us keep the children



safe, while continuing to provide the best possible rehabilitation and support, at all times.

We couldn't do our much-needed work without you. I hope you enjoy this edition of *inspire*.

Thank you.

Amanda Boyd Senior Supporter Care Coordinator

PS Some of the photos in this edition were taken before social distancing guidance.

#### Children at the heart of recovery

 The pandemic is affecting childhood in many ways. We are joining 150+ organisations in a call to Government to put children at the heart of recovery. thechildrenstrust org.uk/children-heart-recovery Add your voice on social media – using #ChildrenAtTheHeart and #PowerOfYouth.



## Summer round up

Summer is here and what better way to cool down and have fun than a water fight! With off-site trips cancelled for now, this is one of the favourite activities for children and staff in Maple and Oak Houses (residential homes). The rules are easy, just get your opponents as wet as possible!

There's more to this than getting soaked in the sun. Water fights help with physiotherapy without the children realising it. For example, the action of drawing up water into a syringe encourages the use of upper limbs and both hands. And it takes eye coordination to aim at the person you want to get wet.

To make the most of the summer, we've taken lots of other activities outside, including the ball pit and our arts and crafts 'glitter' group. Children have been enjoying sensory stories out on the lawn, and our music sensory sessions too (luckily we have no close neighbours)! The young people in Jasmine House also held a Beauty and the Beast themed party in the garden.

#### Kind to the planet and to each other

More of us have been growing our own vegetables recently. Young people in Jasmine House are growing peas, courgettes and sunflowers too. When the produce is ready, they'll package it up for our key workers – including our Child Support Assistants and nurses – to say thank you.



Megan enjoys growing plants for our key workers.

#### Zooming in on excellence

During the lockdown, we turned our successful Professional Showcase sessions into free webinars on Zoom. They share our expertise with fellow professionals who support children with an acquired brain injury, wherever they are in the UK.

It is important that these sessions continue. We are home to the UK's largest rehabilitation service for children with an acquired brain injury, providing the most complex rehabilitation in the UK outside of an acute hospital setting. Our work never stands still and we're looked upon as a centre of excellence. Passing on our knowledge will ultimately benefit many more children and families.



The webinars cover a wide range of topics including spasticity (when muscles tighten and resist being stretched) and dystonia (when muscles contract uncontrollably) in children and an introduction to paediatric tracheostomy. With over 1,400 sign-ups so far, and some fantastic feedback, we're repeating some sessions and launching a second virtual event series.

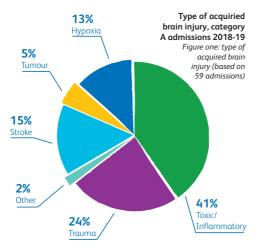
For more information visit thechildrenstrust.org.uk/events/virtualprofessional-showcase

## Spotlight on rehabilitation



Did you know that around 40,000 children experience a brain injury every year? That's one every 15 minutes.

These injuries can be caused by an inflammatory disease like encephalitis, or by an accident or fall, as you can see below. Though some children may be affected mildly or moderately, severe brain injury can be life-changing and children need to relearn everyday things, like eating, walking and talking.



#### Step 1 – referral

The Children's Trust is recognised by the NHS, local healthcare trusts and councils as a specialist in rehabilitation for children who have the most complex needs following a brain injury.

When children are ready to leave hospital, they are referred to our national specialist centre, to benefit from our dedicated facilities and support. They come from all over the UK and have severe physical, cognitive and/or communicative disabilities and challenging behaviours . We welcome some children with moderate to severe needs too. By working with our highly skilled teams, these children and young people have the opportunity to access therapy which enables them to relearn skills they have lost.

#### Step 2 – assessment and goal setting

We assess each child and talk to them and their family about the goals they want to achieve. You can see some of these in this cog diagram – as well as the physical things you might expect, there are personal ambitions too, which could be as simple as seeing friends or being able to make a cup of tea.

#### **Rehabilitation goals**



#### Step 3 – intensive rehabilitation

We build a programme of coordinated support around each child. It involves at least four therapies which could include physiotherapy, speech and language therapy, music therapy and aquatic therapy, plus psychological support alongside education.

Rehabilitation takes place every day as part of a child's daily routine, so that everything they do is focused on reaching their goals.

#### Is rehabilitation successful?

Of the children here in 2018-19:



returned home to live with their families (they often needed to adapt their homes)

- 30
- children returned to mainstream school

15

children moved onto special education

#### What happens in the long run?

We make sure that children and families have support around them when they return home. For 90% of them, we set up a meeting to bring together all the local services who are providing ongoing support. The remaining 10% move on to long-stay and attend our specialist school, or move onto long-stay residential facilities.

#### To find out more at thechildrenstrust.org.uk/ our-services/residential-rehabilitation



After she was hit by a car, Nieve couldn't walk, talk or feed herself. She also struggled with memory loss.

After intensive rehabilitation, Nieve can take steps by herself and her confidence is growing. She also has her voice back.

#### Rehabilitation – Q&A



#### **Q** What is rehabilitation?

- A It aims to give a child their very best chance at making improvements through different therapies or treatments, following a brain injury.
- Q Why do you call rehabilitation 'intensive'?
- A It's not about attending weekly physio sessions, like we may experience following an operation or injury. Our rehabilitation is part of a child's everyday routine, helping them to retrain paths in their brain, often through small, repetitive steps.



Q How many children receive rehabilitation at Tadworth?

- A 96 children received intensive rehabilitation at our national specialist centre last year.
- Q How long does rehabilitation usually last?
- A 93 nights was the average length of rehabilitation programmes.
- Q What's the most important factor in rehabilitation?
- A Children are children, and having fun is the key. When children feel happy they are motivated to work harder (whether they realise it or not!)

#### Rehabilitation can't be stop-start

Your support means we can work with children like Nieve non-stop. thechildrenstrust.org.uk/donate

## Mollie's story

When a lively three-year-old goes down with a bug, you may expect them to quickly bounce back. But when Mollie became ill with a virus in August 2019, it very quickly turned into every parent's worst nightmare.

Mollie was rushed to hospital and, within hours, started to have seizures. It was incredibly distressing for her mum Ceri. "After an electroencephalogram (EEG) test, the doctors told us that Mollie's brainwaves had slowed down and that they were working on a possible diagnosis of encephalitis," explained Ceri. "They did a lumbar puncture and an MRI scan before confirming the worst possible news. Mollie had sustained devastating swelling to her brain."

Mollie was diagnosed with Acute Disseminated Encephalomyelitis, an autoimmune condition that meant the antibodies in Mollie's blood were attacking her brain and causing the swelling. She was transferred to hospital where the consultants explained that the damage to Mollie's brain was considerable.

## "Mollie had sustained devastating swelling to her brain."

"They were extremely worried about her condition and suggested that we prepared ourselves for the fact that Mollie might not make it," said Ceri.



Helen and Mollie making art



Mollie and Ceri supporting our special appeal

Mollie was put on a combination of antibiotics, antivirals and steroids. After 10 long days sitting at Mollie's bedside, Ceri was overjoyed to see her little girl wake up. "When she started to smile and giggle, we knew we had our little girl back," Ceri said.

#### In the best place

It was a massive moment for the family, but the hard work was about to begin. The damage to Mollie's brain was so severe that she had to relearn almost everything – how to hold her head up, sit, roll, crawl, walk, drink and eat again.

The Children's Trust is one of the only places which offers complex rehabilitation outside of a hospital setting. So 12 weeks after being admitted to hospital, Mollie arrived at The Children's Trust.

Mollie had only just started to walk again and was very unsteady on her feet. She got tired very easily and relied on her buggy to get around. Mollie found it hard to coordinate her movements. "She was reliant on me to anticipate all of her needs from food, to dressing, to communicating," explained Ceri.

#### What is Acute Disseminated Encephalomyelitis (ADEM)?

ADEM is a rare inflammatory condition that affects the brain and spinal cord. It happens when the immune system becomes 'mis-programmed', causing immune cells to attack the healthy myelin (a fatty protective coating) which covers the nerves. It usually comes on quickly over hours or days, often following a minor infection such as a cold.

Our rehabilitation team assessed Mollie's needs and put a three-month intensive rehabilitation programme in place – tailor-made for her.

#### Steps to recovery

Through a combination of physiotherapy, speech and language therapy, occupational therapy, music therapy and aquatic therapy, as well as regular psychology and education sessions, Mollie began to make progress here at The Children's Trust.



Mollie's favourite place, our specialist aquatic therapy pool

A real turning point for Mollie was about six weeks in, when she stopped using her buggy to get around and was able to pedal a pushbike with stabilisers completely on her own. "Mollie really enjoyed aquatic therapy and was very motivated. It helped to strengthen her arm, legs and core," explained Krishna, one of our physiotherapists. "Over the course of her rehabilitation Mollie's tolerance improved, allowing us to increase the intensity of therapy. As a result, her mobility and overall physical skills also improved."



Mollie loves dressing up

#### Home at last

To mark the end of her rehabilitation, Mollie rang the 'going home bell' in February this year. "Today, Mollie is a totally different child to the one that arrived here," said Ceri. "She can now walk confidently, even run – which is actually her preferred mode of getting around these days. Mollie has made such amazing progress and it is all thanks to everyone at The Children's Trust.

Now Mollie is at home, she has started to go to preschool three mornings a week, as well as ballet, gymnastics and swimming classes. However, due to current government guidelines, the family are now isolating at home.

"Speech continues to be her biggest challenge due to the verbal dyspraxia she acquired after her brain injury. She does get frustrated, but continues to work hard to communicate with us. Daily telephone calls from our speech therapist has made a huge difference," said Ceri.

"Mollie's strength and determination continues to inspire us every day to be better people. We can't wait to see what her future holds."

#### Our work must not stop

Donations to our special appeal are helping our work continue for children like Mollie during the pandemic. thechildrenstrust.org.uk/donate

## **Our Strategy: Hope and Ambition**

In 2020 we've faced new challenges but we have continued with our ambitious planning – to set us on a path of growth, to reach and support many more children with brain injury and neurodisability.

#### A personal message from Dalton Leong, Chief Executive



I am delighted to share our Strategy for 2020-2025: **Hope and Ambition**. At its heart is our determination to support every child with brain injury and neurodisability, and help them live the best life possible.

Over the last three years, we have built on our clinical and organisational excellence and maintained high standards. 'Outstanding' ratings from the Care Quality Commission and Ofsted Care, and the award of the ISO 9001 quality mark are things we are truly proud of.

It has given us the confidence to set our sights higher, to reach more children, share our expertise more widely and develop new and innovative services. We aim to build upon our experience and expertise to become a world-class centre of excellence, for children with acquired brain injury and neurodisability. We did not write the strategy around a board table, far from it. We embraced know-how and welcomed ideas from everyone from across The Children's Trust, from our experienced clinical team to our kind-hearted volunteers.

Importantly, we consulted families and young people from the very start, their valued input coming from surveys, feedback and forums. So we know it is firmly rooted in the hopes and aspirations of those we support.

#### Our three key aims

### Aim 1 To do more at Tadworth, our specialist rehabilitation centre

Over 33 years we have developed a specialist multidisciplinary team who work together to give young people with highly complex neurodisability the best opportunities possible.

We want to maximise our skills, knowledge, facilities, experience and services to benefit more children than ever before. For example, we will identify, design and launch one new service a year for five years in order to help more children and young people.

More children like Phoebe could receive specialist support at Tadworth.

#### Some comments from young people and families

"Have more social meetings for parents so they don't feel isolated and lonely." "You need a way to spread what you do beyond Tadworth." "The care is second to none but the whole place needs some money investing."

#### Aim 2 To support every child in the UK with an acquired brain injury

Every child with any kind of acquired brain injury, mild to severe, should get good information, advice and support, wherever they live. But it is patchy across the UK.

So we will be scaling up and broadening the support we offer, reaching into communities.

For example, we will build partnerships with major trauma centres, accident and emergency units and other health care services to meet needs beyond our specialist centre in Surrey.

We will also promote wider understanding of brain injury in the community. For instance, helping the public know the signs of brain injury, why that could be life-saving and what

they can do to help.



We could support children like Isaac and his family in their community.

#### Aim 3 Integrating our specialist skills and approaches to benefit children

Children are always at the centre of what we do. So we are going to transform how we deliver services, through a transdisciplinary approach – which means a child's education, healthcare and therapy work seamlessly around their needs.

To do this, we will build a state-of-the-art facility that offers integrated support which is family-centred, helping parents understand their child's needs, involving them in joint planning and supporting the delivery of their child's education.

We could offer integrated education, healthcare and therapy to more children like Mollie.



## A responsible organisation

We care deeply about what we do, and also how we do it. We want to ensure that we are consistently doing the right thing – for the children and young people, for families, for our employees and volunteers, our suppliers and partners and for the environment. So we are investing in our team and monitoring and reducing our costs. We're thinking about our place in the wider community and our impact on the environment. Sustainability will enable more children to access our services.

Find out more about our exciting new strategy thechildrenstrust.org.uk/about/strategy





Service team (taken before social distancing rules).

The second aim of our new Strategy is to reach out to more children in their communities. One way we plan to do this is to expand on the important work of our Brain Injury Community Service, known as BICS.

#### What does BICS do?

BICS is here for children with all kinds of brain injury who would benefit from therapeutic support close to home, to help them get back to everyday life. Last year BICS supported over a thousand children at home, in school,

BICS is key to our ambition to help every child in the UK with an acquired brain injury live the best life possible. at community groups or their local hospital.

New challenges To offer specialist advice and support, the team works closely with children and their parents. Usually it starts with

a phone call, followed by face-to-face visits. So you can imagine how Covid-19 made this more challenging. The team quickly adapted and, from April, offered virtual video visits to families.

Sarah, a member of our BICS team, described how she set up a consultation with a mum and her 13-year-old daughter, who had had a stroke.

#### Virtually face-to-face

"At first, mum was worried her daughter may struggle talking on video to strangers. The family weren't regular laptop users, but when we suggested using WhatsApp they felt happier as they were familiar with it," Sarah explained.

"After the call, mum was amazed how much her daughter had opened up. She told us 'professionals haven't spoken directly to her before'. This is exactly what makes the work of BICS so effective – and it meant we could provide resources and information, and plan this girl's transition back to school."

#### **Positive outcomes**

Most families have welcomed virtual visits. The BICS team now hold their own meetings online, and those with fellow professionals, so they can bring expertise together quickly.

Covid-19 has been a challenge for everyone. But the BICS team have gained valuable insights into new ways of working, that could be here to stay. As always, when it comes to children and their families, we'll do whatever works best for them.

By scaling up our work in the community we can help more children with an acquired brain injury reintegrate into everyday life.

## Callum's camp out

When our usual trips off-site weren't possible due to the pandemic, our amazing team came up with new, fun activities on-site – including socially-distanced bingo and early morning exercises.

But Callum, who has been shielding since lockdown, couldn't join in. So our team thought outside the box, arranging a personal camping trip for Callum inside our grounds at Tadworth.

While Emma and Luisa helped him pack a bag and get ready, other team members set up the tent and made a pond (from a paddling pool) in the garden. Callum had a fantastic day, enjoying a walk around site, fishing and a dance party! Later he did some stargazing in the sensory room, staring up at the projection lights.



After his big day out, Callum received a warm welcome home at Jasmine House just a minute's walk away. Though it felt like he'd been on the trip of a lifetime.

## Gwen's superhero challenge

**V** 

Four-year-old Gwen has been attending Tadworth Tots at The Children's Trust since September 2019. It's our dedicated nursery for young children with a wide range of specialist needs.



Gwen is unable to walk due to nerve damage in her spinal cord. She also has vocal cord palsy and an unsafe swallow, which means that she has a

trachestomy tube to keep her airway safe. But if you think all that stops this determined little girl, think again!

Gwen and her mum Jenny have completed an amazing challenge in aid of The Children's Trust.

Gwen wheeled 2km in her stander, crawled and stair climbed 1km, while Jenny completed a 6km run. Then they covered

11km together, with Gwen in her pram.

The pair have raised an incredible £685 and say it's their way of giving something back. Jenny explains that Gwen has developed a lot since attending Tadworth Tots and adds: "She loves it so much she sometimes refuses to come home!"

#### Did you know?

Our nursery delivers high quality education, therapy and healthcare for children whose health needs are so complex that they cannot be supported in a mainstream nursery. thechildrenstrust.org.uk/our-services/earlyyears/nursery

## Kenny's story

Since 2019, 13-year-old Kenny has lived here in Tadworth at The Children's Trust and attends The Children's Trust School.

Kenny has epilepsy which means his brain nerves can fire abnormally and cause seizures. He also has autism, which affects how he communicates and relates to others.

Mum Jenny said: "The past year has been a huge change for Kenny. We previously lived in the US but due to my job had to move to the UK. I thought a new environment would be really tough for Kenny but he has settled in better than I could have ever imagined. He has made brilliant friends and I'm so happy he can take part in the fun activities at The Children's Trust."

Our School is located at The Children's Trust's national specialist centre in Tadworth. It is one of the only special schools in the UK that provides education, therapy and care exclusively for children and young people with profound and multiple learning disabilities, and complex health needs, just like Kenny's.

#### Who attends the School?

We welcome pupils aged from two years upwards and offer a safe, caring, organised and happy environment where their individual needs can be met. We work in partnership



All of these pictures of Kenny were taken before social distancing guidance.

with parents like Jenny, so that we can enrich their child's quality of life – by giving them the intellectual, physical, emotional and social development that's just right for them.

Kenny is one of around 25 residential pupils at the School, and there are places for some local children who attend as day pupils.

#### What's school like for Kenny?

The curriculum at the school involves a range of activities, including; music and movement, multi-sensory stories, parachute games and light and sound.

Kenny loves Boccia (pronounced bot-cha). If you're not familiar with Boccia, it's a target ball sport which tests both muscle control and accuracy. From a seated position, players throw balls to land as close as possible to a white marker ball, known as the 'jack'.



Ruby helps Kenny build coordination skills.



Kenny playing ball games.

Kenny has a weekly yoga class too, and has sessions which help him with sitting, lying and standing. He is also fascinated with switches and creating an effect, such as turning on lights, activating a blender or hairdryer and propelling his wheelchair forward.

#### More than a classroom

Education doesn't just take place in the classroom, we have lots of ways for the children to explore and learn away from their desks.

- A state of the art aquatics therapy pool
- Playground equipment
- Nature trail
- Woodland walk
- Outdoor musical instruments
- Sensory gardens
- Maze
- Wheelchair-accessible treehouse
- Basketball area

#### Kenny's new normal

Kenny is carrying on his education in a slightly different way due to Covid-19. He is still having lessons but the groups have changed because we're taking extra care to keep children safe with social distancing. At first, Kenny found the change confusing, but he quickly got used to it and was soon smiling at new staff members.

Kenny's teacher, Anne French, says: "Since being in lockdown, Kenny has participated in creative art sessions by making colourful rainbows. Kenny has also continued to enjoy gardening – he has planted sunflowers, tomatoes, chives and strawberries.

"Kenny also took part in a treasure hunt and collected items for his scrapbook. When Kenny finished the hunt, he smiled and clapped his hands together. It was a great moment."



We were delighted to welcome Kenny to The Children's Trust last year.

"We are hoping soon that Kenny will be able to see some of his classmates again, as a few of them are being shielded or are in a different house on site. Kenny is able to have visits from his mother, but great care is given to social distancing."

Kenny's Mum, Jenny adds: "As The Children's Trust has still been operating during Covid-19, I have been really blessed with the opportunity to work all the time at home, knowing that Kenny is well taken care of and can continue to access full educational activities. I am very grateful to each and every one of the staff."

## 100%

of parents agreed their child or young person is taught well in school and has made good progress.

#### "Before we arrived at

The Children's Trust, Kenny was very shy and became uneasy when he would meet new people. Now, he is more confident and will show his excitement with a big smile."

Kenny's mum, Jenny.

## Get involved!

Getting out to fundraise has been more challenging recently. But you've been incredibly inventive, raising funds while having fun. We need you behind us more than ever, thank you!

#### Looking back at Step Forward

In early summer our supporters pounded the streets, gardens, golf courses and more to get their steps up as part of Step Forward. And every step was worth it, thank you.

- Over 100 people, companies, schools signed up
- Together you clocked up over 5,683,618, steps!
- £9,786 raised (with more to come).





Issy Dolby stepped 5,113 stairs after learning to walk again following rehabilitation at The Children's Trust. Read why that's so incredible – thechildrenstrust.org.uk/ issys-story

For 2021 – in a new twist, Step Forward will be challenging our supporters to walk from Tadworth to Tokyo! Watch this space.



#### Be an at-home hero

The coronavirus pandemic is having a devastating impact on our fundraising. So we're relying on our kind supporters more than ever to help.

You can help us by:

- Hosting a virtual fundraising activity with your colleagues, family and friends
- Nominating us to benefit from your school, company or groups fundraising
- Liking and sharing our posts on our social media channels.

Contact us at getinvolved@thechildrenstrust.org.uk to see how you can help.

### **Plans for the future**

#### The Massive Get Together

3 September 2020 Please see details, opposite page. thechildrenstrust.org.uk/events/ The-Massive-Get-Together

#### **Golf Events**

#### 1 December 2020

Our September golf day is full but we still have places at West Hill, Surrey on 1 December. If you'd like to be involved by sponsoring a hole, or donating a prize please contact us. If you'd like to hold your own golf day, we'd love to hear from you.

thechildrenstrust.org.uk/ annual-golf-day-2020

#### **Christmas Concert**

#### 9 December 2020

Holy Trinity, Guildford. Our Celebrity Ambassador Nicholas Owen will host this evening, which we're planning to also show online.

events@thechildrenstrust.org.uk

#### A question of...



Phil Tufnell, our celebrity ambassador, hosted a live-streamed quiz on Facebook and YouTube. One of the picture rounds featured well-known people sporting PPE. With Phil as host, it was packed full of laughs. Over 200 people tuned in, raising an impressive £1,400!

#### Marathons in 2021

**28 March** – London Landmarks Half Marathon **11 April** – Royal Parks Half Marathon

#### Brighton Marathon – 18 April 2021

An uplifting run through parks, past the famous Pavilion and along stretches of coastal roads with panoramic views. thechildrenstrust.org.uk/events/ brighton-marathon-2021

#### London Marathon - 3 October 2021

Run 26.2 miles through the streets of London with one of our guaranteed places. thechildrenstrust.org.uk/london-marathon

Own-place runner? Please join our team! challenges@thechildrenstrust.org.uk

Please check our website for the most up-to-date information thechildrenstrust.org.uk/ upcoming-events



Elaine Paige OBE, our ambassador for almost 40 years, has recorded a special charity single, a cover of 'Sing a Rainbow', in support of The Children's Trust.

"I have recorded the song with the children on video call and mobile phones, which has been great fun! I am very proud to have been able to record this song for a charity I love while in lockdown." said Elaine.

The children have severe disabilities and complex needs. They worked really hard to learn the song and to pronounce the words clearly. It was great fun learning the signs and drawing rainbows. As well as having a good time, it helped with their rehabilitation too.

## Single OUT NOW!

Download the single now

Find it on Spotify, iTunes, Amazon Music and Apple Music and all major download platforms. All proceeds from sales will go to help The Children's Trust. For information visit thechildrenstrust.org.uk

#### Visit Elaine's fundraising page

Elaine has also set up a JustGiving page for anyone who would like to donate **justgiving.com/fundraising/elaine-paige**