



THE TANGRAM

SPRING / SUMMMER 2022



**CEREBRAL
PALSY** CYMRU

THERAPY AND SUPPORT FOR CHILDREN AND THEIR FAMILIES
THERAPI A CHEFNOGAETH I BLANT A'U TEULUOEDD



CAKE & TEA FOR CP

GET BAKING IN MAY & HELP US RAISE SOME DOUGH!

Celebrate our 30th Birthday with us by rolling up your sleeves, firing up the oven, and baking some tasty treats to make every crumb count!

Whether you decide to host a coffee morning, organise a bake sale for family and friends, challenge your colleagues to a staff bake-off, or simply catch up with friends and family over a cuppa and some biscuits, every cake baked and pound donated really will make a difference.

Scan the QR code or visit:

www.cerebralpalsycymru.org/events/cake-tea-for-cp to sign up and receive your free fundraising pack which is jam-packed full of materials and ideas to get you off to a flying start!



Cake & Tea for CP 2022 is kindly sponsored by

 **Harding Evans**
solicitors

Welcome to the spring/summer 2022 edition of The Tangram

Hello reader,

I hope that this newsletter finds you well and that you are enjoying the first signs of spring.

As a charity we are, can you believe, approaching our 30th birthday, which will take place on Sunday 12th June.

As part of our birthday celebrations, we will be launching our 30th birthday appeal, 'For Every Little Life,' to raise £30,000 towards ensuring that we can see every baby who needs us this year.

Last year 62 babies and their families received our vital early intervention service. We know that if babies at risk of cerebral palsy have to wait, before being seen by us, then the window of opportunity to make the greatest change to their future outcomes, which occurs during the first two years of life, gets smaller. We don't want this to happen to any family.

Throughout the year there will be many ways that you can join in with our birthday celebrations and support the children and families who need our services. One of the highlights is Cake & Tea for CP in May, where many people at work, in the community or at school hold a cake sale or bake-off competition to fundraise for us.

We would love to invite you and your family to join us at our 30th Birthday Bayside Walk in June. I hope you can make it!



I am also thrilled to announce the completion of our building appeal and I would like to extend my thanks to all of you who donated. We look forward to finishing phase two of the work on our fantastic new children's centre and to its official opening later this year.

I hope that, as you read this newsletter, you will feel inspired to join us in celebrating our 30th birthday in some way and make sure that we are here this year 'For Every Little Life.'



Jenny Carroll
Centre Director & Consultant Physiotherapist



Ymddiriedolaeth
Genedlaethol
National Trust

#BlossomWatch at Dyffryn Gardens



On Saturday 12 March, a few of our families were invited to visit Dyffryn Gardens to mark the launch of a new partnership between National Trust Cymru and Cerebral Palsy Cymru.

To celebrate the National Trust's annual #BlossomWatch campaign, as well as the start of this special partnership, Bedwyr, Aman, Imogen, and Mary, along with their siblings, planted two blossom trees and hundreds of snowdrops in the arboretum at Dyffryn Gardens near Cardiff.

Mary, who is eleven years old, was thrilled to be a part of such a special occasion.

"This is my first time to Dyffryn Gardens. I have been getting my hands dirty planting trees and snowdrops. It has been a really fun day. I want to come back again and we are going to see them blossom every year!"

We are thrilled to announce that, as part of our partnership, National Trust Cymru will be helping to transform the outside of our new children's centre over the next few months by creating a new wellbeing garden for our families and staff members.

Rebecca Williams, Assistant Director at National Trust Cymru, is delighted at the prospect of helping us create an accessible and family-friendly green space right on our doorstep!

"The pandemic showed us the importance of having access to nature and the outdoors, from gardens and parks to green spaces in workplaces and within communities. The Covid-19 crisis also highlighted significant inequalities in access to nature within urban areas.

Working with partners, we aim to increase access to green spaces in and around urban areas, so that more people are within easy reach of quiet places for reflection with wide open skies."



Scan to watch the video of our
planting at Dyffryn Gardens!



National Trust Cymru will also be providing free access passes to families right across Wales, which will help the conservation charity to review some of the accessibility challenges at places they care for.

Rebecca Williams continues:
"Visiting your favourite Trust places should be an enjoyable and inclusive experience for everyone and we are proud to be working with Cerebral Palsy Cymru to review some of the barriers at places we care for."

"We strive to meet the different needs and expectations of our supporters and work hard to improve accessibility, however, we recognise we have a long way to go, but we're determined to be there for everyone, forever."

Our ambassador, Lucy Owen, was also able to join us for the planting and had a wonderful time chatting to our families and helping them with the planting.

Lucy was drawn to the National Trust's #BlossomWatch campaign when writing her book 'Flower Girl' and the partnership blossomed from there.

"It is pure magic for me to see these two brilliant charities working together and doing something so wonderful. We've learned during the pandemic how nature can help us all through difficult times and the importance of being outdoors."

"I'm so pleased that National Trust Cymru sites are being made accessible for everyone, and I can't wait to see the blossom trees bloom in the new Cerebral Palsy Cymru centre wellbeing garden. I feel very proud that something so special has grown from small seeds planted in 'Flower Girl'."

We are really excited to work with National Trust Cymru over the coming months and see our new wellbeing garden come to life!





"It's so lovely to see the babies begin to socialise and interact with each other during these sessions. I also enjoy seeing the parents meeting each other and sharing their stories. They start to share useful information with each other and friendships and support begins quite naturally at our playgroup. It's a privilege to be involved with our young babies and families in this way."

Glenys Evans
Family Support Coordinator

"I always look forward to our monthly playgroups and welcoming new families. I particularly enjoy watching how babies begin to interact with each other and respond to new play activities. It is so lovely to see their personalities shine through!"

Gosia Jon-Dare
Senior Physiotherapist

Play time at Better Start Together!

Our Better Start Together is a playgroup that welcomes families with babies 0-2 years who attend our specialist early intervention programme 'Better Start, Better Future.'

The monthly playgroup provides an opportunity for families to meet together whilst they engage in a variety of play activities with their babies.

Each session is facilitated by Glenys Evans, our Family Support Coordinator, and either Gosia, one of our Physiotherapists, or Marissa, our Occupational Therapist.

The idea of the playgroup came in 2018, based on feedback from our families who found it challenging to find a playgroup suitable for them and their children in their local communities.

At Cerebral Palsy Cymru, we recognise the importance of looking after the wellbeing of the whole family, as well as the children. Families who experienced a difficult time around the birth of their child are often under significant stress, with parents frequently reporting feeling overwhelmed and isolated on their journey.

Better Start Together provides opportunities for interaction with other babies and adults during shared play, something many families experience for the first time.

All play activities are individually adapted to reflect each baby's age and abilities, and support development of their communication, attention, sensory and motor skills.

One of the biggest benefits of attending the group, according to feedback, is the opportunity for parents to meet other families who can share experiences and relate to each other's stories.

We are excited to see our playgroup grow and welcome along new families over the coming months, as well as seeing some familiar faces!



30TH BIRTHDAY BAYSIDE WALK

Celebrating Cerebral Palsy Cymru's BIG Birthday!

SUNDAY 12TH JUNE | 2:30PM START

START & FINISH @ THE SENEDD, CARDIFF BAY

£10 ADULTS | £5 CHILDREN

This flat, 4.5k route is perfect for all ages and abilities to walk with us and celebrate our 30th birthday!

Everyone who takes part will receive a commemorative medal, and party bags will also be provided for children.

To register for the event, scan the QR code or visit www.cerebralpalsycymru.org/events/30th-birthday-walk



A gift in your Will

For those babies yet to be born

We want our services to be there for every one of the estimated 70 babies born each year at risk of cerebral palsy. We know that there is only a short window of time, the first two years of life, when our specialist therapy can make the biggest difference to their future. We don't want any child to miss that opportunity.

Around 80% of the funding we need has to come from donations, gifts in Wills, retail, and fundraising activity. In other words, we are very much dependent on the kindness and generosity of people like you.

Gifts in Wills have helped us, over the years, to grow and develop, as we are able to put the money where the need is greatest.

After you have provided for your family and friends, you might like to consider leaving a gift in your Will to Cerebral Palsy Cymru. A gift of any size in a Will can be life-changing for the future of children in Wales who have cerebral palsy.



We'd love to know if you are thinking about making, or have already made, a gift in your Will to us – we will of course keep whatever you say confidential.

- I have already included a gift to Cerebral Palsy Cymru in my Will.
- I intend to leave a gift in my Will to Cerebral Palsy Cymru.
- I would like to find out more about leaving a gift in my Will to Cerebral Palsy Cymru and would like to receive a Gift in Wills guide.

If you would like to request a Gift in Wills guide, please complete the contact details below, cut out this page and return it to us using the free-post envelope enclosed.

Name:

Address:

Postcode:.....

Mobile No:

Email:.....

If you would like to talk to someone about leaving a gift in your Will please contact Emma Brooks, Trust & Legacies Fundraising Manager, on 02920 528104.



Collaborative learning to ensure a better start for babies

An insight into the Early Intervention and Assessment Course and its benefits for both course participants and families.

Dr Sally Jary, Clinical Lead for Early Intervention at Cerebral Palsy Cymru, shares the importance of the Early Intervention and Assessment Course for both course participants and the families attending with their babies who have been identified at risk of neurodevelopmental challenges.

What is the Early Intervention & Assessment Course?

The early intervention course is for paediatric physiotherapists, occupational therapists, and speech and language therapists working in neonatal units and early years settings in the UK and overseas.

As a result of the COVID-19 pandemic, the course has evolved into a blended format of online presentations and tutorials, followed by unique face-to-face practical early intervention therapy sessions hosted by Cerebral Palsy Cymru.

Coordinating the facilities and ensuring the smooth running of the practical sessions requires a huge collaborative effort. I would like to thank all of the team at Cerebral Palsy Cymru involved in liaising with, supporting and welcoming families who attend with their babies, organising adequate lecture and therapy facilities that comply with everchanging COVID-19 social distancing restrictions and, of course, ensuring there is enough tea, coffee, milk and biscuits for families, course participants, and course leaders!

Thank you also to our therapists at Cerebral Palsy Cymru (Gosia Jon-Dare PT, Marissa Mount OT & Catharina van der Walt S<) and Glenys Evans, Family Support Co-ordinator, who provide valuable additional multi-disciplinary therapy advice and support during the practical sessions.



Working collaboratively with our professional colleagues

The early intervention course is led by Christine Barber, Consultant Physiotherapist, and Betty Hutchon, Consultant Occupational Therapist, who have led early intervention courses nationally and internationally for many years.

Christine is a widely known and respected physiotherapist with huge experience supporting and advising families, children and adults with neurodevelopmental challenges across the lifespan.

Betty is Head of Children's Occupational Therapy and Physiotherapy at the Royal Free Hospital in London and is known internationally in the field of early assessment and intervention. She is an important driving force behind EiSMART (www.eismart.co.uk) which has informed and helped us further shape our specialist early intervention service 'Better Start, Better Future.'



The positive impact the course has on the families who attend as part of the practical sessions.

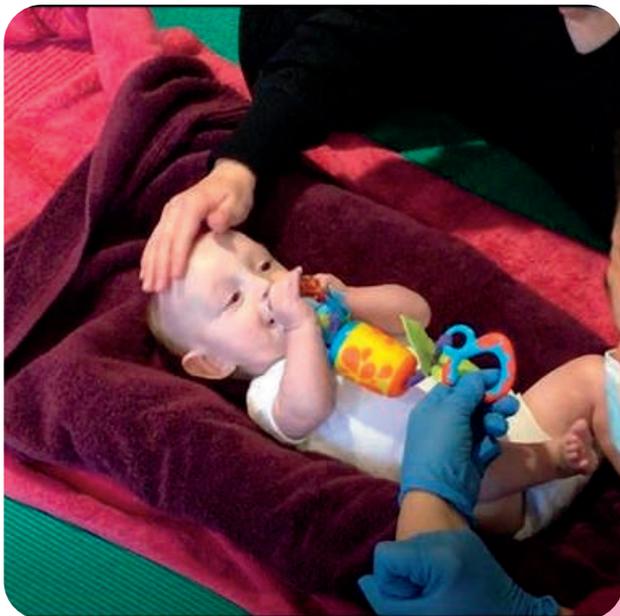
The families who attended the course with their babies worked with course participants over 6 sessions during the practical part of the course.

The families enjoyed learning together with the therapists and were integral to discussions and the clinical reasoning process throughout the course.

A further added benefit is that many of the families go on to remain in touch with each other through attending 'Better Start Together', our monthly family playgroup. It is wonderful to receive feedback from the families who describe the positive changes they see in their babies over the duration of the course.

Leah and Mark are the parents of Noah, one of the babies who attended the practical sessions on the most recent course. Noah was born 10 weeks early and spent nearly 2 1/2 months in the neonatal unit before being discharged home.

We first met Noah in November 2021 when his paediatrician suggested the family contact Cerebral Palsy Cymru to find out more about our specialist early intervention service 'Better Start, Better Future.'



Following an initial consultation session with Noah and his parents, we offered Leah and Mark the option of attending the early intervention practical sessions with Noah in February.

We were delighted with the feedback that we received from them both during our initial session and following the course, and I would like to end by sharing it with you.

"Thank you for inviting us! I learned so much and I came away feeling so much more validated, understood, and confident in the care I provide to Noah."

My journey as a mother of a premature baby has been fraught, and I can honestly say that I have felt respected, listened to, and involved during the early intervention therapy sessions at Cerebral Palsy Cymru and during the Early Intervention and Assessment course.

Noah also did some things I didn't know he could do, which goes to show that the right support and education can work wonders.

When I feel confident and happy so does my baby and it's been a long time since I felt that positive and Noah certainly responded. That gives me so much hope for the future."

To find out more about the training courses that we offer, please visit:
www.cerebralpalsycymru.org/for-professionals
or email info@cerebralpalsycymru.org

Build a Better Future Appeal - 1 year on

Our appeal was launched in May 2021 to help us raise funds to complete the second phase of refurbishment needed at our new children's centre in Llanishen, Cardiff.

We are absolutely delighted to announce that, thanks to the generosity of our supporters, we have successfully raised the £450,000 needed to complete the refurbishment of our new children's centre!

It has been just under 12 months since we launched our Build a Better Future Appeal, and we have been overwhelmed by your warm response and kind words about our new home.

The second phase of the refurbishment will begin in May and will see key features being added including a lift, partition walls in our therapy rooms, hoists and a complete redevelopment of the forecourt including a canopy over our family parking spaces, re-tarmacking and fencing.

Our sincere thanks go to so many for making our dream of a new children's centre a reality, with a special thank you to the Moondance Foundation and Welsh Government for understanding our vision and investing in our future.

We would also like to thank The Bradbury Foundation and Garfield Weston Foundation for their generous gifts which took us over the finish line.

We aim for the work to be completed in October this year, in time for the official opening of our children's centre later this year.



A huge thank you to everyone who supported our appeal:



The Bradbury Foundation,
Hong Kong



And everyone who kindly made a donation online or via our spring/summer 2021 newsletter appeal

Fundraising corner

As a charity, we need to raise £1.8M every year to provide our current level of service, and over three-quarters of our income comes from fundraising activities and charity retail sales.

Trekking to Everest base camp to make a difference.

On April 29th, our long-standing supporter, Ashok Aggawarl of CHP Accountancy, will be setting off on the trek of a lifetime to Mount Everest base camp.

Back in 2018, Ashok successfully trekked to the base camp of the third highest mountain in the world, Mt Kanchenjunga, raising several thousand pounds for us.

His journey to Everest base camp will take 17 days and he can't wait to take on the challenge to raise even more funds for us.

"Over the 17-day trekking trip in Nepal, I will experience some of the most beautiful mountain landscapes and incredible views of Mount Everest. The stresses of altitude sickness and walking for several hours a day in cold temperatures has not deterred me. This will be a challenge of a lifetime and a dream come true and I am thrilled to once again be raising funds for Cerebral Palsy Cymru who do such important work with families across Wales living with cerebral palsy."

Ashok has already raised an incredible £1,660 for his Everest base camp trek, and we are sure that his friends, colleagues and family will support him in his fundraising efforts to reach his final target of £3,000.

We would like to say a huge good luck to Ashok as he embarks on his trip of a lifetime, and we can't wait to hear all about it when he returns!



South Wales Freemasons show support for our early intervention service 'Better Start, Better Future'

We'd like to thank the South Wales Freemasons who have recently awarded us a grant of £59,400 to fund 22 babies for the next three years to have a specialist therapy consultation, in total benefiting 66 babies and their families.



Robert Payne from South Wales Freemasons, said:

"I'm very pleased we've been able to help Cerebral Palsy Cymru with their excellent programme of therapy for children living with cerebral palsy. These babies will have the best possible start in life and the greatest opportunity to reach their potential."

The grant from South Wales Freemasons comes through the Masonic Charitable Foundation, which is funded by Freemasons, their families and friends, from across England and Wales.

Welcoming our volunteers to our new children's centre

We were thrilled to finally be able to invite our volunteers to our children's centre to have an exclusive tour of our new home and have a catch up with our fundraising team over a cuppa and a biscuit.

Our volunteers work hard to ensure that we can continue to raise funds via our charity shops and events. Their enthusiasm and dedication to us as a charity means so much, and it was great to catch up with some of them in person last month.



Over the course of the afternoon, we gave them a short presentation around the importance of our rebranding as an organisation, and how they play a key role as ambassadors for the charity. We also shared with them the success of our online charity shop, powered by Thriftify, and how our charity shops can work in partnership with our e-commerce team to raise even more funds from the donations that we receive to our charity shops!



Celebrating our partnership with The Royal Mint

We would like to take this opportunity to celebrate our 2-year partnership with The Royal Mint which sadly drew to a close at the end of March.

We have had an absolutely amazing time getting to know their dedicated team who have taken on fundraising activities with enthusiasm and gusto, despite it being hard to arrange normal fundraising activities through the pandemic.

The team at The Royal Mint have raised an incredible amount of money for us over the past two years by hosting quizzes, teddy raffles, baking events, and much more.

A highlight of our partnership was having the opportunity to invite some of our families from across South Wales to visit Santa at The Royal Mint's Santa Experience last Christmas. Our families had the most magical time, and our children and their siblings got the chance to meet Santa in person and receive a Christmas gift from him.

As a last hurrah and fundraising event, a team of 32 employees from The Royal Mint took on the fastest seated zip-wire in the WORLD at Zipworld Tower Colliery Site near Aberdare. Reaching speeds of up to 70mph(!) the team raised a fantastic £4,008 to add to their final total - they certainly ended their fundraising for us on a high - and at speed!

We'd like to extend our warmest thanks to Ryan Mogg, a staff member at The Royal Mint, for nominating us to be considered for their charity of the year scheme and for all of his colleagues who voted for us. Thanks also to Kim Brown, charity champion extraordinaire, who would always gather the troops and hold a fundraising bucket in our name. We are thrilled that Alyssia, Ryan's daughter, who has cerebral palsy and who has attended our children's centre for therapy, will be accepting the cheque on behalf of the charity with her dad at The Royal Mint next month to mark the end of this wonderful partnership.



SNOWDON TRIPLE CHALLENGE

10.5 MILE CYCLE. 9 MILE TREK. 2.5 MILE KAYAK.

Take on the ultimate challenge in North Wales this September for Cerebral Palsy Cymru.

16-17th September 2022. £85 registration. £395 minimum sponsorship.

For further information please contact:

T: 02920 522 600

E: Fundraising@cerebralpalsycymru.org

CH>RITY
CH>LLENGE

RUN FOR US!



Lace up your trainers and walk, jog or run to help make a difference to children across Wales living with cerebral palsy.

Whether it's 5k, 10k, half or a full marathon... whatever the distance, we would love it if you would run in aid of us.

Our fundraising team will be on hand to support you every step of the way, and you will get a free running vest to wear with pride when you pledge to raise £100 or more!

We will also provide you access to our dedicated runners Facebook group, so you can meet fellow runners and share your training tips - as well as that all important medal selfie at the end.



Upcoming races...



Cardiff Half Marathon

2nd Oct 2022

£20 reg fee £250 min sponsorship



Virtual London Marathon

2nd Oct 2022

£20 reg fee £150 min sponsorship

Or alternatively, find a race you would love to run and get in touch to find out how you can run it in aid of us!

To register for a charity race space, or to enquire about any of the events listed, please email fundraising@cerebralpalsycymru.org



LLONGYFARCHIADAU! CONGRATULATIONS!

We would like to say a HUGE THANK YOU to everyone who took part in our '70k Your Way Challenge in March'!



Together, you completed thousands of kilometers and raised an incredible £27,185 for us! Thank you for helping us make a difference - you are all fundraising superstars!



"With each block of therapy we would have a discussion about a goal, and by the end of the fortnight, it would be achieved."

Gail, Roman's mum, shares her story.

"My son, Roman, was due to be born by planned C-section at 32 weeks following signs on a scan that he had become severely anaemic due to Rhesus Haemolytic disease. He was, however, delivered in an emergency due to foetal distress.

Within a few hours of birth, I was told to prepare myself for the worst and encouraged to take photographs of him as it was unknown whether he would survive. In the hours following a double exchange transfusion, the first of its kind in Singleton Neonatal Intensive Care Unit in over 7 years, he became unrecognisable as the baby I had given birth to earlier that day, as the severe jaundice had caused his skin to become very dark, almost black in colour.

We spent five and a half weeks at Singleton NICU and, when Roman had seemingly made a full recovery, and breastfeeding had been established, I was told that we could leave for home. A full 'MOT' was carried out on Roman before our planned departure, and the last test to be carried out was a cranial ultrasound scan. At the time I was not concerned, as comments had been made about how strong and advanced he was, lifting his head up and looking around, and that he was very alert. However, when the doctors approached me with a sombre look on their faces following the results of the scan, and a nurse was standing nearby with a box of tissues in her hand, I knew something was wrong.



I was informed that the ultrasound had shown the progress of cystic changes on the left side of the brain since the last scan and the damage was covering a significant area. The potential for future implications for Roman's development were explained to me, although it was made very clear that it was impossible to predict the severity at that point. Of course, this came as a huge shock.

An MRI scan confirmed significant encephalomalacia (softening or loss of brain tissue) involving most of the left side of the brain. In the follow up appointment the Consultant Paediatrician pointed to the large white area and explained that 'this is where his brain should have been.'

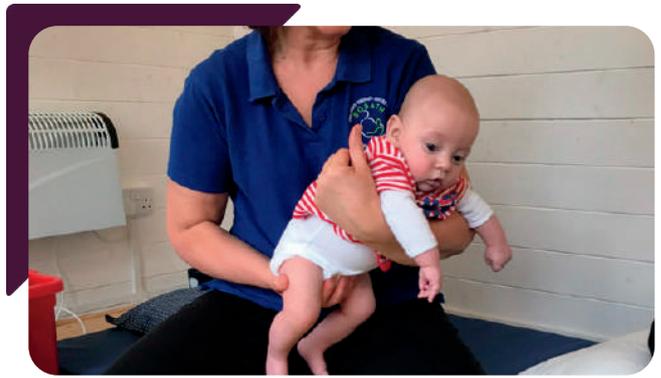
After being at home for a few weeks, our local Physiotherapist, Jane, explained to us that there was an organisation called Cerebral Palsy Cymru who specialised in helping children like Roman who had suffered brain injuries at birth and who were at risk of being diagnosed with cerebral palsy. She asked if I would like to be referred to their services and of course I agreed.

At 5 months old (3 months corrected age for prematurity) Roman had his first appointment at Cerebral Palsy Cymru to begin a block of therapy on their early intervention service, 'Better Start, Better Future.' I had absolutely no idea what to expect, however, we were given such a warm welcome and I was put completely at ease immediately.

On the first visit we discussed Roman's background, behaviours, routine and over the course of the two week block of therapy I was taught how to handle Roman, how to position him to sit and sleep, and I learnt the differences of caring for a child with cerebral palsy. The therapists at Cerebral Palsy Cymru could already see the difference in Roman's posture, something which was impossible for my untrained eye to see. Without this early understanding that was given to me by them, I would have been completely clueless as to how to care for a baby with cerebral palsy.

As the months passed, Roman's disability became visible and it was apparent that he was not using his right hand. Eventually, he was officially diagnosed as having right sided hemiplegia cerebral palsy. With each block of therapy that came around, every 3-4 months, we would have a discussion about a goal and what I hoped to achieve from the block and each time, by the end of the fortnight, it would be achieved. I would leave the centre full of new play ideas and we would practise what we had learnt at home.

Alongside receiving therapy, we were also invited to attend the monthly Better Start Together playgroup sessions and coffee mornings. These sessions were a great opportunity to chat to other families undergoing similar experiences to us.



When Roman was 27 months old, he was still unable to walk unaided. We were invited for a block of therapy at the centre during the fortnight before Christmas. Not only did he get spoilt with Christmas gifts from Cerebral Palsy Cymru, but on Boxing day, Roman took his first independent steps. What a wonderful Christmas present for us and it was all thanks to them.

Today, Roman is a happy and active 4 year old. He is non-verbal at present, but is progressing slowly and surely with his speech thanks to his Cochlear implants.

We love being a part of the Cerebral Palsy Cymru family and enjoy taking part in fundraising events to raise money for them. We are extremely grateful to have them in our lives and that Roman continues to benefit from their exemplary knowledge and guidance."



Our 30th birthday appeal

Celebrate our 30th birthday with us this year and help us be there 'For Every Little Life.'

On the 12th June 1992, our charity, Bobath Cymru (as it was known then) was founded by a small group of families to ensure that children living with cerebral palsy in Wales could have access to specialist therapy and support, that was at the time only available if you travelled to London.

Fast forward 30 years and we have grown from a small team with only 4 therapists and 45 children on our caseload, to a caseload of over 900 children and 15 therapists, having provided thousands of specialist therapy sessions to hundreds of children and families right across Wales.

We are now called Cerebral Palsy Cymru, and our mission is to improve the quality of life of all children in Wales living with cerebral palsy.



Our ambition for the future is to develop and grow our services so that we can make sure we are there for every baby and child who needs us, not only now but throughout their childhood. This ambitious dream can only be possible with your support.

As our Centre Director, Jenny, mentioned in her welcome address, we are currently experiencing an unprecedented demand for our services, in particular, our specialist early intervention service 'Better Start, Better Future.' We know that if babies at risk of cerebral palsy have to wait to be seen by us, then the window of opportunity to make the greatest change to their future outcomes, during the first two years of life, gets smaller.

To mark our 30th birthday, we are launching our 'For Every Little Life' appeal, which will help us ensure that we can see every new baby that is referred to our services this year. Throughout the year, there will be lots of ways for you to get involved with our 30th birthday celebrations – check out the opposite page to see how you can help us mark this momentous year and ensure we can be there for every little life that needs us.



Glenys, our Family Support Coordinator and Founding Parent of the charity, reflects on the past 30 years of our history.

"I was one of a group of founding parents that joined together to open a children's centre for families in Wales to have access to specialist therapy, as at the time this was not available to those who lived here in Wales.

Many of us had to travel to and stay in London for two-week periods, which was often difficult and expensive. We also felt there would be enough children living in Wales who had cerebral palsy to have our own national centre.

Bobath Cymru, as it was called back then, opened on 12th June 1992, just 2 years after we launched the charity.

When the children's centre first opened, we employed just 4 therapists and 2 admin staff, and the first 45 children to be offered appointments in Wales joined us on a journey that would change my life forever.

The charity has been my second family for over 30 years now and means so much to me and all my family. My children have grown up with the charity and I am so proud of all that Thomas, my son who has cerebral palsy, has achieved while benefitting from the therapy at our centre.

I can't really believe that 30 years have passed and I feel proud that we are achieving such a huge milestone anniversary this year!

The charity simply would not be here today without the determination and drive of the founding parents and many others who joined us along the way. Each of the trustees, staff members both past and present, and supporters have helped the charity to grow and I am so proud of everything we have achieved together.

I am really looking forward to celebrating our 30th birthday in many different ways with our families and supporters this year.

Although we are not planning on hosting a Summer Ball this year, as we so often have in the past, I think it's even better that we can have a very special family fun walk together on 12th June in Cardiff Bay. I hope many, many families and supporters will join us and I'm sure it will be a trip down memory lane for many - I hope to see you there!"

Ways that you can get involved to help celebrate our 30th birthday!



Make a special birthday gift to us

You can show your support and make a special birthday gift to us by donating to our 30th birthday appeal. Every pound donated will take us closer to our £30,000 target.

To be one of the first people to make a birthday gift to us and kickstart our birthday appeal, please fill in the donation form that you received with this newsletter, or visit our website to make an instant gift.

Join us on our 30th Birthday Bayside Walk

We are throwing a party and you're invited! Join us on Sunday 12th June at Cardiff Bay for our 30th Birthday Bayside Walk. The flat, accessible 4.5k route will take us around all the iconic sites of Cardiff Bay and everyone will receive a medal and goodie bag upon finishing. It's certainly going to be a celebration! Register online via our website or check out the advert in this newsletter on page 6 for more information.



Pledge to make a difference 'For Every Little Life'

Setting up a regular gift will help make sure that every child with cerebral palsy that is referred to our service this year, and for years to come, will get the best possible start in life.

By making a donation of £30 a month, or whatever you can afford, you will be helping to fund a specialist therapy session this year for a baby who has, or is at risk of having, cerebral palsy. These specialist therapy sessions are vital to ensure that every little life has the best start possible, and the best future.



**Because we know.
Together we can
make a difference.**

About Cerebral Palsy Cymru

We are a national centre of excellence for families in Wales with children who have cerebral palsy. Our specialist team of physiotherapists, occupational therapists and speech and language therapists work together to offer transdisciplinary skills, so each child benefits from their combined expertise. We also offer a family support service which provides a listening ear, advice and support to those who need it.

To find out more about us as an organisation, please visit
www.cerebralpalsycymru.org

 info@cerebralpalsycymru.org

 02920 522 600

 [Facebook.com/CerebralPalsyCymru](https://www.facebook.com/CerebralPalsyCymru)

 [@CP_Cymru](https://twitter.com/CP_Cymru)

 [@CP_Cymru](https://www.instagram.com/CP_Cymru) [@CP_Cymru_shop](https://www.instagram.com/CP_Cymru_shop)

 [/CerebralPalsyCymru](https://www.linkedin.com/company/CerebralPalsyCymru)



NOMINATE US AS YOUR 2022 CHARITY OF THE YEAR

Do you or one of your friends and family know of a business that hosts a Charity of the Year scheme? Nominating us for 2022, will not only help make a huge difference here at Cerebral Palsy Cymru, but it can be a unique and fulfilling experience for all involved.

"We have worked alongside The Royal Mint as their charity partner for almost 2 years and the staff have come up with some really creative and fun ways to raise funds, even when the more conventional fundraising options have, of course been off the table. Over the years I have seen companies thrive on the challenge of fundraising for us with everyone finding activities to suit them. From bake sales to talent auctions, bike rides to hikes, we've seen it all! In return, we are able to offer tangible examples of how the money raised is being spent and making a difference to families. We are excited to see what 2022, and indeed future years, hold for us and we would love to share that experience with our new Charity of the Year partners!" Claire Walker, Corporate Relationship Manager

If you, or the company you work for, would like to nominate us as your 2022 Charity of the Year, please contact Claire for more information.

Clairew@cerebralpalsycymru.org

02920 522 600

THANK YOU! DIOLCH!



Come explore the jungle with us!

"We love getting to know all of our 'Jungle Explorers' and their families. Each and every one of them brings something unique and positive to the project. There was a particular favourite moment for me this year that I would love to share with you. The children had made party food for their families, and they then had to carry this on a tray along the length of a corridor into the family room. When entering the room, the families broke into spontaneous applause for each child. It showed real group spirit and the children were so visibly proud of themselves. If you understood how difficult carrying a tray is for some of these children, you would have been proud of them too!"

Marissa Mount
Occupational Therapist

Our Jungle Explorers project, which is kindly funded by BBC Children in Need, has been specifically developed for children who have unilateral cerebral palsy, where one side of their body is more affected than the other. It's a fun and age-appropriate way of providing intensive upper limb intervention, with the aim of developing the child's ability to use both hands more effectively for functional tasks.

At the start of the project, the children and their families identify functional goals which are meaningful to them that they would like to work on and improve. These can range from activities such as being able to dress more independently, using cutlery to make a sandwich or open a packet of crisps, climbing stairs, or riding a bike.

This year, our 6 jungle explorers took part in several group sessions, as well as receiving 1:1 therapy where they worked in pairs and with their therapist to develop their individual skills.

The group sessions have an emphasis of working together as a team, having fun, and socialising. Our therapy team adapt the activities for each specific individual as much as possible, ensuring that each individual gets the most out of both the 1:1 and group sessions.

An integral part of the project is providing the children the opportunity to socialise with other children who have unilateral cerebral palsy.

All of the children included in the programme attend a mainstream school which means that they may have never met another child who has similar abilities and who experiences similar challenges to them. A huge value of 'Jungle Explorers' is that the children have an opportunity to share their successes and challenges, often common amongst the whole group, in a safe environment.

"My daughter really enjoyed the programme and we saw a huge change in her confidence levels, as well as a massive improvement in the use of her left hand and the strength in her left leg. She was excited to meet other children with similar conditions and really enjoyed the course and making friends."

LLONGYFARCHIADAU! CONGRATULATIONS!

Well done to all our 2021 Virgin London Marathon runners!
We are all so proud of you!



Run for us!

Lace up your trainers to take on a running challenge in aid of us. Whatever the distance, we promise to support you every step of the way.

Email fundraising@cerebralpalsycymru.org to find out more about our 2022 runs and races.

Independent Living Skills 2021

Find out more about our ILS project which aims to give young people living with cerebral palsy the chance to work on their skills and become increasingly independent as they approach adulthood.



Hello! We are Charlotte, Chase and Rhys - three young people living with cerebral palsy. We all attended the Independent Living Skills (ILS) project in August and wanted to share with you our own personal experiences of that week. ILS is a project run by Cerebral Palsy Cymru that gives young people like us living with cerebral palsy the opportunity to develop skills and increase our independence. We hope you enjoy reading our blogs and finding out a little more about us.



"My name is Rhys and I am 13 years old. I find it ok having cerebral palsy. I just persevere and do the things I want to do. I was really happy when I was asked if I wanted to take part in the ILS programme.

I saw taking part in the ILS project as a great opportunity to work on my skills, in particular making myself a drink and something to eat. These were the goals I wanted to work on – I also wanted to practice my football skills.

Every day at ILS we had a group discussion and then we would go and work on our own goals. On the last but one day, we went out as a group together to the shops and then to McDonald's. That was really good fun.

My favourite activity for the week was gardening. I like gardening and enjoyed getting out all the weeds and planting the flowers. If you get the chance to go on the ILS programme at Cerebral Palsy Cymru, take it. You never know when you will get the opportunity again and it's really good fun. It helped me learn new skills and build confidence when going out."



"Hi my name is Charlotte and I have just turned 15, I use both my wheelchair and walker to get about. I was very excited when asked if I would like to attend the Independent Living Skills project at Cerebral Palsy Cymru.

As day one approached, I began to feel quite apprehensive, as these sessions were going to be very different to the therapy sessions I had attended in the past. I was also going to be meeting other teenagers with CP, not something I was used to doing!!

On the first morning, I ate my breakfast nervously and got in the car. We arrived at the new centre and what can I say, it was amazing, a lovely bright new reception, manned by a few familiar faces, and fantastic therapy rooms!

We found out that we would be working as a group and individually on everyday goals we wanted to achieve, but we would be doing this without our mums or dads! As a group, we all wanted to work on everyday things and gain more independence, like making and carrying a cup of tea or washing our hair, which might sound easy but for us, it can be quite tricky! Some of us had goals around putting our makeup on more easily and one day we had a visit from Spectrum cosmetics. We were treated to our very own personal makeup lesson, which was fantastic!!!!

On another day we all ventured out shopping, some of us for the first time. We looked at how we could get there and how we were going to navigate around, some of us with wheelchairs. It was all very exciting as I'm a shopaholic!

Overall this was a fantastic experience and it was lovely to make new friends and chat about some of the things that are difficult for us, that others might not understand, along with achieving goals that make life a little more easier. Thank you for helping me gain more independence."

"Hello everyone, my name is Chase I am 15 years old, and I have cerebral palsy. Personally, I get tired easily as walking can be difficult. I do struggle speaking to people about my cerebral palsy and also I struggle with making friends, and sometimes it makes me feel like I am alone with this condition. It has always been a big insecurity of mine.

When I was first asked to take part in the ILS project, I felt excited because it would give me an opportunity to meet and speak to others with cerebral palsy and work with the therapists at Cerebral Palsy Cymru.

As a group we all talked about our feelings when in different situations and we did group work around this. I made a strawberry cheesecake by following a recipe, which was one of my goals, and we all made milkshakes. One of the days we all went out shopping as a group and then afterwards we went to Mcdonalds, which is next to the centre. My favourite activity was when I made the cheesecake as I felt so proud of myself afterwards.

My anxiety and confidence in talking to others about my cerebral palsy has improved since taking part in ILS. I was given tips on how to cope with my anxiety such as breathing exercises, and the advice and support that I was given by therapists and other teenagers that attended meant that I became more confident and I am now able to talk about my cerebral palsy.

To others that are reading this, please don't ever feel like you are alone because you're not. Being different is okay. Yes, it can be a challenge for all of us young people living with cerebral palsy, but we are all strong and we can do anything - don't let anyone tell you you can't."



Fundraising corner

Celebrating all the ways people across the country come together to help raise funds and make a difference to children and families living with cerebral palsy.

Our fundraising heroes in the community

We love hearing about our supporters' fundraising stories and would like to share some of our favourite community fundraising stories from the past 6 months with you all.

Audrey, Susannah, Matthew, and Peter organised an August Bank Holiday community cake sale and by the sounds of things, their homemade goodies went down a treat!



"Our street decided to celebrate the end of lockdown by having some social time in their front gardens on the Bank Holiday Weekend. As part of that, I decided to host a cupcake stall because I love baking and I

thought it would be a good way to say hello to people on the street I hadn't met before. Our cakes sold out really quickly (I should have made more!) and we raised £135 in just a few hours!"

Thompsons Solicitors, who have adopted us as their Charity of the Year, took on a mammoth fundraising challenge across August to celebrate their centenary year. Between them, the team ran over 500k, completed 100k steps, baked 100 cookies, surfed 100 waves, rowed/biked 200k, and swam 400 lengths/6.5 miles as part of their 100 Challenge to celebrate their centenary year. Together, the team has raised a fantastic £1,060!

On the theme of Charity of the Year, we were delighted to receive the news that Cardiff Rotary Club have kindly nominated us as their charity for 2021. Their members, lead by Michael Brook, are now busy raising funds and awareness for us in their local community and we would like to thank them for thinking of us when making their selection.

Although the past year and a half has been difficult for many of us, our fundraisers have still managed to find inventive ways to raise money and support us whilst abiding by lockdown restrictions and social distancing.

Sue, who is a staff nurse at a hospice in West Wales, set herself the challenge of walking the Wales Coastal Path at the start of this year and completed her epic walk last month.

"I initially began walking during the first lockdown in 2020 as I was unable to go swimming and quickly found that I enjoyed the time I had to myself. In January I set myself the challenge of walking the distance of the Wales Coastal Path. However, as we were once again back in lockdown, I had to complete my challenge virtually. At the beginning of my challenge, I had to start my walks from home and I decided that if I had a charity to walk for, I would be more motivated to keep going and achieve my 870-mile target. I chose Cerebral Palsy Cymru as I had heard about their 'Build a Better Future' appeal for their new children's centre and wanted to support this fantastic project. Once lockdown was lifted, I was able to walk on the coastal path and my walks became more scenic. Even though I have completed the 870 mile challenge, I haven't stopped walking as I still really enjoy the quiet time it gives me! I can't wait to see the new children's centre once it is completed - I am sure the children and families will love it."



The wonderful world of charity retail

Our four charity shops, based in and around Cardiff, are responsible for around 37% of our charitable income every year. They really are a hive of fundraising activity!

Mowgli's Street Food Cardiff celebrate reaching £20k!

Mowgli Street Food Cardiff adopted us as their in-house charity partner back in the autumn of 2019. Despite the ups and downs that the hospitality industry has faced, their customers have continued to support us by adding £1 on their bill, which is then kindly donated to us each month.

We are thrilled to announce that they have now reached a phenomenal £20,000 through this donation scheme, which is an incredible achievement.



The Mowgli Street Food restaurants across the country have raised almost £1 million to date for local causes, and we are proud to be a part of their family. Our fundraising team are certainly Looking forward to celebrating with the staff at the Cardiff restaurant and enjoying a chat bomb or two!



Looking through the window of our charity shop



You never know what you might find when you pop into your local charity shop. From designer handbags to rare vinyl records, there are many special and unusual items tucked away on the shelves.

Our charity shops play a huge role in our fundraising activity, and prior to the pandemic were consistently generating around one-third of the charity's total income. That's a lot of donations and sales!

Since they were able to reopen on 12th April, our shops have brought in a remarkable £167,151 despite the challenges they have faced as a result of restrictions.

"I am so grateful to all of our donors, customers, shop staff, and amazing volunteers who have all played a part in helping to ensure that our shops have re-opened successfully and, of course, safely after what was an extremely challenging and worrying time when we were closed for over 4 months during the winter lockdown" said George Parry, Senior Retail Manager. "Our shops are very much part of their local communities and it is so nice to be able to welcome people through the doors once again."

We are especially thrilled to see so many of our regular volunteers back behind the tills and busy sorting through donations behind the scenes, and we want to say a huge thanks to those of you reading this! Without our volunteers' continued hard work and dedication, we simply wouldn't be able to open the doors to our shops every morning and welcome our customers in to see our gems of second-hand goodies.



theBigGive

CHRISTMAS CHALLENGE

30 NOV—7 DEC 2021

One donation. Twice the impact.

Once again at the start of December we will be taking part in the Big Give Christmas Challenge. This year, we have decided to set ourselves our most ambitious fundraising target to date and are aiming to raise £20,000 in just 7 days to help fund our early intervention service for babies who have or are at high risk of cerebral palsy.

Why have we done this? Because quite simply, those babies and families, like Cora and her mum Jennifer, need our support now more than ever.



Cora's story

“Cora was born full term and was diagnosed with hypoxic ischemic encephalopathy (HIE), which is essentially oxygen deprivation and a lack of blood flow to the brain which occurred during labour. Cora underwent cooling therapy for 72 hours after she was born, in an attempt to slow down her rate of brain damage.

Her paediatrician has only in the last few months confirmed he believes she has cerebral palsy, although the signs have been there since the very early days.

Cora was around 10 weeks old when we had our first session with Sally and Glenys. We instantly felt at ease and as if we had found exactly who we were looking for. We felt we finally had direction and something positive to focus on with Cora. It's very hard when you are told to just 'wait and see' how your child develops, so we felt we were at least doing our very best for her development and future. Our first therapy session was over zoom as this was early on in the pandemic in August 2020. We then went into the centre in person the following month for a session.

Each session would typically start with a general catch-up to work on how Cora has been doing and discuss any concerns or focuses we would like for the session ahead. We very much go with her mood as well and try keep her interested and as happy as possible. Most of the time she has great fun!



I only stumbled across Cerebral Palsy Cymru whilst frantically googling for services in our area one evening. I felt that there had to be something out there for children like Cora where no formal diagnosis had been made and I was very happy to find that there was! I filled out a self-referral form on the website for their 'Better Star, Better Future' early intervention programme and heard from Glenys (the charity's Family Support Coordinator) shortly after.



From that day we feel we have been part of the Cerebral Palsy Cymru family, and we have not looked back. Glenys, and Cora's therapists Sally, Gosia and Rina have been our go-to people for any questions from day one. There is such a lack of resource and advice out there for children who are not 'neuro typical' so the team have really been a fountain of knowledge. Things like the physiotherapists helping select appropriate toys, Glenys has discussed sleep problems with us and advice on filling out a Disability Living Allowance form. All of these helpful 'extras' that we appreciate so much that have supported our family.

Cerebral Palsy Cymru have made an enormously positive impact on our family. Everyone we have met has been so supportive and helpful to us, we couldn't have wished for more."

This Christmas, you have the opportunity to have your donation doubled by making it via the Big Give Christmas Challenge. Thanks to the generous match funding scheme, which has been made possible by The Hospital Saturday Fund and our long-standing supporter Derek Redwood, every donation will be doubled. If you would like to make a special Christmas gift to help make a difference to babies and their families, like Cora and Jennifer, please visit www.thebiggive.org.uk between 12pm 30th November and 12pm on 7th December.

You can also sign up to our emailing list by scanning this QR code or by visiting www.cerebralpalsycymru.org/newsletter to receive a reminder for the launch of the 2021 Big Give Christmas Challenge.



Don't miss the chance to have your donation doubled and make a Christmas gift that will last the whole year.

