



# We are Cerebral Palsy Cymru.

We are a registered charity and national centre of excellence.

Our mission is to improve the quality of life of all children in Wales living with cerebral palsy.





# Centre Director & Chairman's message

2022/2023 was a special year for us as we celebrated our 30th birthday. Over the past three decades, Cerebral Palsy Cymru has provided specialist therapy and support to thousands of children and families across Wales living with cerebral palsy.

Cerebral Palsy Cymru's reputation as a leader in the treatment and management of cerebral palsy is growing beyond Wales, supported by our pioneering early intervention service 'Better Start, Better Future', which provides specialist therapy for babies and children from birth to two and a half years of age.

Cerebral Palsy Cymru was set up by a group of dedicated and determined parents 30 years ago. Their dream of opening a children's centre here in Wales for their children, and many other families, became a reality on the 12th June 1992, and this year we have taken the time to reflect and celebrate all that we have achieved together since then.

3 decades on, our charity's mission is still the same - to improve the quality of life of all children in Wales living with cerebral palsy - children like Chester, whose story you can read further on in this report. Chester is just one of the 76 babies who was referred to our early intervention service last year. This is the highest number of baby referrals we have seen since the programme launched in 2015, and we predict that the demand for this service will only increase.

This increased demand for our services, combined with rising costs, has created a challenging environment in which to operate and has placed huge pressure on our financial and staff resources. We want to be there for any family that needs us, which is why growing our income continues to be a priority. We are delighted therefore that we have made 2 critical appointments this year - appointing Marie Wood to the role of Director of Fundraising & Communications, and Marc Roberts to the position of Head of Retail. Marie, Marc and the rest of the Senior Leadership Team will work closely with our Board of Trustees to navigate the financial challenges ahead and to develop a sustainable business model.



Looking ahead to the future, our goal over the next 10 years is to increase our capacity and resources to be able to see more children of all ages at each critical milestone but to fulfil this ambition requires financial support from both the public and private sectors.

Once again, we would like to extend our heartfelt thanks and gratitude to our Volunteers, Staff, Trustees, Fundraisers & Supporters for their continued hard work, commitment, energy and support. Although we acknowledge that there will be challenging times ahead, we truly believe that, together, we can continue to make a life-changing difference to children and families in Wales living with cerebral palsy.



Jenny Carroll MA MCSP PGC(HE) Centre Director





I Frank Holmes Chairman

Visit www.cerebralpalsycymru.org or follow us on social media for more charity updates, fundraising news and stories from our families and service users.



/CerebralPalsyCymru O @cp\_cymru









You can also sign up to receive our monthly eNewsletter: www.cerebralpalsycymru.org/newsletter

## **OUR YEAR IN NUMBERS 2022-2023**

1,054 therapy sessions were delivered by our specialist therapy team.



babies were referred to our

specialist early intervention service

children across Wales received therapy and support from us.

family support sessions took place with our dedicated Family

raise a fantastic £389,934

training courses were facilitated and delivered by our therapy team to

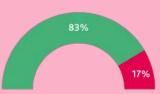
professionals from across the UK and around the world!

The income we need to secure every year is approximately

# £2Million



On average each year, 83% of our income comes from donations. gifts in Wills, trusts, our charity shops, fundraising events and corporate donations. Around 17% of what we need comes from statutory sources.





This year saw the highest number of babies referred to our services ever! In total, 76 babies were referred to our specialist early intervention service 'Better Start, Better Future'. Currently, our focus remains on early intervention. Research shows that the earlier a child who has, or is at high risk of having cerebral palsy, receives specialist therapy, the greater the impact on that child's future outcomes.

Where resources allow, we provide our specialist therapy and support to children and young people up to the age of 18, as therapy can make a significant change to all age groups. We do this in a number of ways, often in partnership with local health boards across Wales, by delivering face to face therapy at our children's centre in Cardiff, virtually for those families who are unable to travel for therapy, or in local therapy locations closer to the families home.

Overall, we provided 1,054 therapy sessions across Wales in 2022-2023. 834 of these were at our children's centre or online, and 220 took place in one of the seven health boards across the country.

Delivering therapy in partnership with our NHS colleagues is a really important part of what we do.

Our outreach programme sees our therapy team travel across the country, from Hywel Dda University Health Board in West Wales, to Betsi Cadwaladr University Health Board in North Wales and even Cardiff and Vale University Health Board closer to home.

Delivering therapy in the community provides us with the opportunity to work more closely with NHS Community Therapists from all over Wales, developing relationships and helping to improve the skills of local teams by providing them with personalised learning opportunities while working in partnership with our specialist therapy team.



We understand that in some areas in Wales, not all the therapy disciplines (physiotherapy, occupational therapy and speech and language therapy) get to work closely together and so our therapists often provide advice and therapy, demonstrating transdisciplinary working, to ensure that children living with cerebral palsy and their families receive the help and support they need.

As a charity, we understand the importance of therapy, and know the more money that we raise, the more therapy we can provide. This is why we are extremely grateful for the charity partnerships that enable us to provide children from a range of ages and difficulties with unique and enriching experiences. Projects like our partnership with National Trust Cymru, who built the sensory and wellbeing garden at our children's centre for our families to enjoy and children to use as part of their therapy sessions, and BBC Children in Need who funded our ESCAPADES! Project.



### **ESCAPADES! 2023**

In April and November 2022 and March 2023, thanks to funding provided by BBC Children in Need, we were able to provide 9 young people, who have a Classification of Level IV/V on the Gross Motor Classification Scale (GMFCS), with specialist therapy sessions as part of our ESCAPADES! Project.

Each young person attended individual sessions tailored to their personal goals, as well as group activities which focused on participation, communication and social skills, using the framework of our different senses – looking, listening, feeling, moving and tasting.

For many young people who have severe cerebral palsy, socialising and participating in society is often incredibly hard. All of the young people who attended our ESCAPADES! group were non-verbal and communicated to some degree through facial expressions, vocalisations, eye-pointing using both low- and high-tech communication system.



Our ESCAPADES! project provided time for social interaction with the other participants, facilitated by our therapists. By listening to the young people and their parents and hearing what they would like to get out of the group sessions, our therapists devised activities that every young person would be able to access and participate in together.

One of the highlights for our March ESCAPADES! group was having the chance to explore our sensory garden in a planting session, exploring and using our senses of Touch, Smell and Vision.

"During this session, the young people got the opportunity to play with textures they had not really experienced before like wet soil and tickly or spiky plants. It was wonderful to see the young people so engrossed in helping us plant the cherry blossom tree, alongside the National Trust Cymru gardeners" said Helen Burnsford, Project Lead for ESCAPDES! and one of our Speech & Language therapists. "Everyone had so much fun, and we are so lucky to have these facilities available to us to incorporate into therapy sessions, making them as varied and fun as they possibly can be!"





# ENSURING FAMILIES ARE AT THE HEART OF OUR ORGANISATION

Cerebral Palsy Cymru was set up for families, by families, in 1992. Glenys Evans, our Family Support Officer, is one of our founder parents and has been involved with the charity since 1989. During this time, she has undertaken numerous roles including secretary to the steering committee, trustee, and volunteer.

She joined our staff team in 1998 and has been helping our families ever since. Glenys' son Thomas (now 40 years old) has cerebral palsy, meaning she has a wealth of knowledge and understanding to share with the families who attend our centre.

We understand that having a child who has cerebral palsy affects the whole family, including family members such as grandparents, aunts and uncles. As an organisation we aim to make our services 'family centred' and keep the family at the heart of everything we do. We want to make sure that our families feel supported and empowered so that they can help their child in the best way possible, and one way that we do this is by providing our Family Support Service free of charge to any family that needs it.



Glenys facilitated 132 1:1 family support sessions across the year, the majority of which were for families of babies under the age of 2 years. She was also the first point of contact for the parents and guardians of the 76 babies that were referred to our early intervention service 'Better Start, Better Future.'

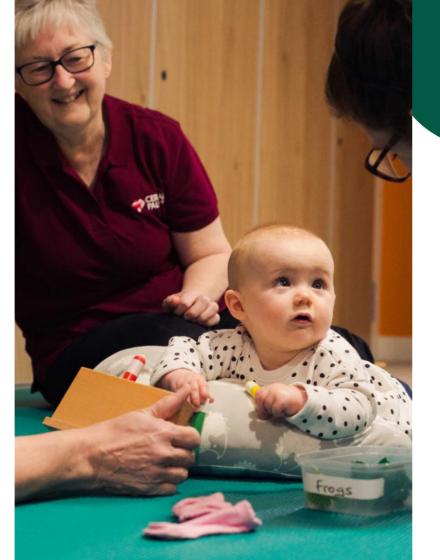
"If you have any concerns about your baby or young child, I'm here to listen to you and help the best I can" says Glenys. "You may have experienced a traumatic birth, or your child may have recently been given a diagnosis of cerebral palsy and you might be unsure what this means. I am also here for those parents who have an older child and just want to talk with another parent who has experienced bringing up a child with cerebral palsy. Whatever the concern. I am here to help."

#### If you would like to find out more about our:

- Family support service
- Better Start, Better Future (for babies up to the age of 2 ½ who have or are at high risk of cerebral palsy)
- Better Start Together Play Group (for babies up to the age of 2 ½ who are currently accessing our early intervention service)

Please contact Glenys Evans:

Glenyse@cerebralpalsycymru.org 02920 522 600.



### **CHESTER'S STORY**

Chester is one of the 500 babies who have been referred to our specialist early intervention service, 'Better Start, Better Future' since we launched the service at the end of 2015. His parents, Richard and Charlotte, have kindly agreed to share their family's story to demonstrate how 'Better Start, Better Future' has a positive impact on families across Wales.

"Chester was born at 27+1 weeks very unexpectedly and was delivered at home by his dad, weighing just 1.18kg. He was rushed straight into the Neonatal Intensive Care Unit (NICU) and although at first he seemed to be breathing ok on his own, within 24 hours he had stopped breathing which lead to him being resuscitated. This in turn led to a grade 3 and 4 bleed on his brain.



Chester's time in NICU was full of ups and downs and was a rollercoaster of emotions for us. He caught e-coli and had numerous blood transfusions, oxygen ventilation, lumbar punctures and ventricle taps to help drain the excess fluid on his brain.

After 102 days in NICU, Chester arrived home on oxygen. This was a scary time for us both, but our outreach nurse visited every week to help and support us. Each week we saw his oxygen dependency lower and eventually, after 3 months, Chester came off oxygen support altogether. We were first told about Cerebral Palsy Cymru by our consultant Rachel, when we were discussing his coming home plan.



Rachel mentioned about the charity's early intervention service 'Better Start, Better Future' that helped babies just like Chester. Once we left hospital, Cerebral Palsy Cymru's family support coordinator, Glenys Evans, contacted us for an initial discussion, and it was only a few weeks later that we were booked in for our first session.



During our first visit, Gosia, one of Cerebral Palsy Cymru's specialist therapists, and Glenys listened to our story and provided us both with much needed support, listening to our worries and concerns. They gave us exercises to help Chester develop based on what our goals as a family were. We felt a sense of relief and positivity coming out of our first session, that we were able to have that support and that the future was not so daunting.

Since that very first therapy session at Cerebral Palsy Cymru, we have seen a huge improvement in Chester's development. When he first started his sessions, he would rarely use his right hand or turn his head to the right. However, thanks to the therapy he has received, Chester is now starting to use both his hands. The knowledge you gain by working alongside Cerebral Palsy Cymru's specialist therapy team helps you understand how the brain works and why certain things may be a challenge for babies like Chester.

The help and support you gain from these therapy sessions are simply incredible. By using what we learn during the sessions at home, we have seen Chester go from strength to strength. He is a very determined little boy, and the early intervention therapy and family support has helped our family so much.

A lot of parents who have premature babies are worried about what the future may hold, and like us they simply want to give their child the best possible help and support.

'Better Start, Better Future' just does that – it gives parents the help and support they need to give their babies the best possible start in life.

We would like to thank everyone who has helped Chester on his journey so far. Without Cerebral Palsy Cymru, none of this would have been possible. The support they have given to us as a family has been invaluable and they have given us so much hope. We know that ultimately, this service is provided to families like us thanks to the donations that Cerebral Palsy Cymru receives, and that without 'Better Start, Better Future' we wouldn't have Chester here with us the way he is today."





More than 80% of our income now comes from donations, gifts in Wills, trusts, our charity shops, fundraising events, and corporate partnerships and donations. We therefore continue to be hugely grateful to all our supporters for helping us to make a life-changing difference to children and families living with cerebral palsy across Wales.

During 2022/23, we adjusted to the 'new normal' after the COVID-19 pandemic, and were thrilled to see our events calendar come alive once again. From flying through the air on zipwires at Zip World Aberdare, enjoying delicious homemade bakes with families and friends throughout May for 'Cake & Tea for CP', and a spot of Christmas shopping at our Christmas Mini Market, to taking to the streets of Cardiff to run the Cardiff Half Marathon, it was wonderful to once again be able to offer a range of fundraising activities and events for our friends, families and supporters to help us raise vital funds.

Throughout the summer months, we also hosted a number of special events to mark our birthday year, such as our 30th Birthday Walk which saw over 150 of our families, friends and supporters come together to share their own personal stories and experiences with one another as we walked together around Cardiff Bay. We also invited our founding parents, a group of remarkable individuals who fundraised and petitioned to establish a specialist children's therapy centre here in Wales for their children and many other families, to our new home in Llanishen for a long awaited catch up and celebration.

Digital fundraising and the growing popularity of Facebook fundraising challenges played a significant role in recruiting new supporters to our charity, and we were thrilled that over 160 individuals from across Wales, and further afield, actively participated in one of our two Facebook fundraising challenges throughout the year, 125 of them fundraising for us for the first time.

Although the cost-of-living crisis and rising energy costs dominated the headlines in the weeks leading up to Christmas, we were thrilled that our supporters were still able to come together to help us once again reach and exceed our Big Give Christmas Challenge target. Thanks to the match funding support from The Hospital Saturday Fund, Barratt Homes, and The Simon Gibson Trust, we raised £23,814 in just 7 days to help fund our early intervention service 'Better Start, Better Future'.

As we moved into 2023, we were proud to once again be the leading voice in Wales to show our support for Cerebral Palsy Awareness Month throughout March. A particular highlight was welcoming our newest ambassador, Welsh Paralympic Athlete, Olivia Breen, to our children's centre to meet the young people participating in our ESCAPADES! group.

Throughout the year, we continued to nurture the special relationships that we have with our corporate partners, and would like to thank Slater and Gordon, Mowgli Street Food, (cont.) St Joseph's Hospital, Hugh James, Blue Self Storage to name just a few. Their support for so many of our events, campaigns and appeals throughout the year is incredible.

Trusts income continues to be one of our largest sources of support. We would like to extend our special thanks to the Moondance Foundation, the Masonic Charitable Foundation, BBC Children in Need and the Garfield Weston Foundation in particular for their vital support.

As a charity that works tirelessly to ensure that our families are at the heart of everything that we do, we are proud to report that for every £1 we spend on fundraising activity, we generate £5.





As we look to the future, the rise in referrals and increasing costs will mean that we will need to continue to grow fundraising income. The Senior Leadership Team and Board of Trustees are currently looking at how we can develop a more robust and sustainable business model for future years.

In addition to strengthening our fundraising income, our five-year strategy is to work towards securing Welsh Government support for our early intervention programme, 'Better Start, Better Future', to invest in our training provision by developing more online courses and to develop a self-funded therapy service alongside our charitably funded provision. We will also grow our retail operation, opening a fifth shop in 2024 and taking on additional sites in subsequent years.





# THE WONDERFUL WORLD OF CHARITY RETAIL

As a charity, we are supported by a small, but growing number of unique charity shops based within Cardiff, the Vale of Glamorgan, and Rhondda Cynon Taff. Each of our shops specialises in re-selling preloved items that are generously donated to us by members of the local community, and the proceeds raised from the sales of these items go on to generate approximately 26% of our overall fundraised income.

2022/2023 was the first year since before the COVID19 pandemic that all our shops were able to trade a full 12-months without any restrictions or closures. Not only did this enable us to generate a total of £445,949 in income, but it also allowed us to welcome back many of our volunteers and regular customers.

In total, over 144,000 pre-loved items were sold through our 4 shops and online retail platforms in 2022/2023. If they had not been donated to charity, a lot of these items would have ended up in landfill sites. In addition to the pre-loved items that we re-sold, we also recycled over 80 tonnes of items that were deemed unsalable throughout the year.

"The Charity Retail Sector is seeing big growth driven mainly by economic, environmental, and social factors" says Marc Roberts, who joined us in January 2023 as our new Head of Retail. "Gone are the days when shopping in a charity shop was considered lesser, buying pre-loved items is on trend and we are seeing younger customers shopping alongside our regular customers searching for high quality, affordable items more and more each day. It's great to see shops busy and full of activity again. Charity shops are vitally important, not only for the



organisations that they support by delivering income that is unrestricted, but also for the environment at large and for local communities. I am looking forward to developing our retail strategy and helping Cerebral Palsy Cymru deliver great, sustainable retail long into the future."

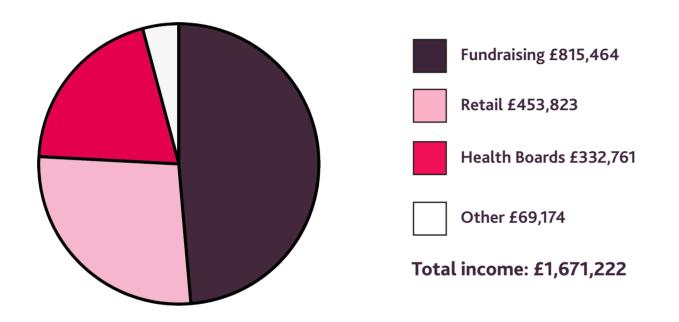
We would like to take this opportunity to thank all our retail volunteers and staff for the many hours they spend carefully sorting though and processing the tens of thousands of items donated to our shops each year, serving customers with a smile, and dedicating their time and experience to help us continue to make a difference to children and families across Wales living with cerebral palsy.

Scan the QR code with your smartphone camera to watch a video of our volunteers sharing the positive impact that volunteering has had on them.





## BREAKDOWN OF INCOME AND EXPENDITURE





In addition to the income detailed on the opposite page, we were fortunate to have income in previous years which was given to cover projects and expenses in this financial year.



In 2022/2023 we provided 1054 sessions to 293 families. We received 179 responses to our parent feedback forms which are completed after every intervention, with the following results:

- 100% rating the quality of our service between 8-10 out of 10
- 100% rating their satisfaction with the therapy session they received as 8-10 out of 10.
- 100% rating the level to which the therapy session had contributed to the knowledge and understanding of their child's needs as 8-10 out of 10.
- 94% seeing a positive change in their child's abilities as a result of the therapy sessions, for example, "He is now exploring taking his weight on his knees and also using his arms to pull himself along which he didn't do before the session."
- 100% saying of families saying 'yes', the therapy session has addressed their concerns, whether partially, to a large extent or completely.
- 100% of families finding our Family Support Service 'valuable,' "I cried the first time I spoke to Glenys. I felt like it was the first time I was really listened too. I will never forget that."

We received 51 responses to our annual Family Support Survey sent out to parents/carers in July 2022. Responses came from across every health board area in Wales, with Cwm Taf Morgannwg making up the largest response base (33%). We learned that:

The most popular answers, with over 65% of families selecting them, to the question 'How has our Family Support Service helped you during your time at Cerebral Palsy Cymru' were; Provided information and advice on how to access support for your child; Provided practical support; and Given you hope for the future.

The most popular answers, with over 74% of selecting them, to the question 'If you attend our Better Start Together monthly playgroup, how has attending it helped you?' were; Increased your child's social interaction; and Increased your opportunities to socialise with other parents/carers.

47% of families said they hadn't received support for their family from anywhere else other than Cerebral Palsy Cymru. After establishing our evidence-based early intervention service, 'Better Start, Better Future', in 2015 we have now seen 470 babies and their families to date from all parts of Wales. Our early intervention programme has an international reputation for excellence, with requests to visit the centre from as far afield as Brazil, Belgium, Spain, and Singapore. We have also been invited to present our work at an international conference in the field in Slovenia in May 2023, invited by the European Early Intervention Special Interest Group.

We are also co-leading the development of the Cerebral Palsy Register for Wales to collate data to help facilitate better planning of services, housing etc, raise standards of care and ultimately reduce the incidence of cerebral palsy. This work will result in Wales being the first nation in Great Britain to have a Cerebral Palsy Register.

We have an international reputation for our knowledge, skills, audit studies and training providing training programmes to upskill therapists in Wales and, increasingly, across the world. We also present the impact of our work and the results of audit studies to international conferences, contributing to Wales' growing reputation as a world leader in the treatment and management of cerebral palsy.





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