# THE TANGRAM AUTUMN / WINTER 2023





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

# MARCHNAD NADOLIG CEREBRAL PALSY CYMRU CHRISTMAS MARKET

DYDD SADWRN **2<sup>®</sup> RHAGFYR** 11AM-2PM

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#### **MYNEDIAD AM DDIM**

LANT STALLS | RAFFLE | KIDS CRAFTS CAKES | FESTIVE TREATS AND MUCH MORE!

### 🗰 FREE ENTRY

SATURDAY

2<sup><sup>md</sup></sup>DECEMBER

11AM-2PM

CEREBRAL PALSY CYMRU CHILDREN'S CENTRE, 1 THE COURTYARD, 73 TY GLAS AVENUE, LLANISHEN, CARDIFF, CF14 5DX

NODDIR GAN / SPONSORED BY

HUG<mark>H | J</mark>AMES

### Dear Friends,

Welcome to this special 'Better Start, Better Future' edition of 'The Tangram'.

As I write this, we have just had the 500th baby referred to our specialist early intervention service, 'Better Start, Better Future'! To commemorate this significant milestone, this editon of the tangram will focus on all the work we do around early intervention, and the fundraising effort needed to provide this vital service. We are continuing to see an increased demand for our early intervention service, which is fully charitably funded, so we depend heavily on the generosity of supporters like you to make it possible for every baby to be seen. Thank you for helping us to reach this incredible milestone!

We have recently celebrated National Welsh Charities Week - a week that recognises the good work of charities, social enterprises, voluntary organisations and community and volunteer groups in Wales. In October, we were thrilled to be announced as a finalist for the 2023 Welsh Charity Awards, organised by the WCVA, in the Health and Wellbeing category. From feedback data, we know that 96% of families are seeing a positive change in their child's abilities as a result of our specialist therapy, and being shortlisted for this prestigious award was a wonderful acknowledgement and celebration of the positive impact that we are making on the health and wellbeing of children and families, across Wales, living with cerebral palsy.

I am sure that you and your family are already starting to prepare for your Christmas celebrations, and we are looking forward to seeing many of you at our Christmas Market at our children's centre on Saturday 2nd December.



This Christmas, we are pleased to be once again taking part in The Big Give Christmas Challenge and, starting from Tuesday 28th November at 12pm, we will have just 7 days to raise £16,000 which will help fund 'Better Start, Better Future.' Every donation made until we reach our target will be doubled at no extra cost to the donor, thanks to our match funding pot from NFU Mutual Llandeilo and the Reed Foundation. If we are successful, 27 additional babies will be able to benefit from a specialist early intervention therapy session so please consider making a donation!

We have also enclosed some tickets for our Christmas raffle, which is sponsored by Hugh James, and would be so grateful if you could sell these to your families and friends, or purchase some for yourself, and send the stubs and donations back to us using the freepost envelope enclosed. There are a number of excellent prizes available, and all the money raised will help us make a lifechanging difference to children and families across Wales living with cerebral palsy.

In case I do not see you at one of our Christmas events, can I take this opportunity to thank you for your continued support, and I would like to be one of the first people to send you and your family our best wishes for the festive season.

Jenny Carroll Centre Director and Consultant Physiotherapist.



### **Chester's Story**

Chester is one of the 500 babies that has 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 a donation made to us this Christmas will have a life-changing impact on the families who access this vital service.

"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.

Inplythat – it gives parents the help and<br/>support they need to give their babies<br/>the best possible start in life.vethe best possible start in life.engthWe 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.

'Better Start, Better Future' just does

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."





# Have your donations doubled this Christmas thanks to The Big Give Christmas Challenge!

From 12pm on Tuesday 28th November, we will have just 7 days to raise £16,000 to help us fund 'Better Start, Better Future' - our specialist early intervention service that provides therapy and support to babies and their families across Wales, like Chester and his family.

Every donation made via The Big Give Christmas Challenge during this time will be DOUBLED at no extra cost to yourself. That means £10 becomes £20, £50 becomes £100, £150 becomes £300 - Christmas magic!

We will be sharing direct links to our online campaign page across our social media channels between 28th November and 5th December.

Scan the QR code below with your smartphone camera to complete a short form and a member of our fundraising team will be in touch with you when the campaign is live to provide you with all the information to make a donation and have it doubled thanks to the Big Give Christmas Challenge.



(please note - donations will only be doubled during the campaign week. please do not make a donation prior to 12pm on 28th November)





## What is Cerebral Palsy?

Cerebral palsy is an umbrella term that describes a group of conditions affecting a developing infant or child's brain.

### How common is it?

It is the most common physical disability in children worldwide. It is estimated that in the UK around 1 in every 400 children will be diagnosed with cerebral palsy. There are around 30,000 children living with cerebral palsy in the UK today.

In Wales, around 70 babies are born every year who will have cerebral palsy and it is estimated that 1,800 children are living with the condition.

Cerebral palsy can be classified in many ways, including by functional ability, distribution, or type of tone.

### Parts of the body affected by cerebral palsy







The whole body is affected

which may include the

muscles of the face

and mouth

Unilateral/Hemiplegia One side of the body is affected

Bilateral/Diplegia The whole body is affected with the arms and upper body affected to a lesser extent

# The difference we made to children and families across Wales living with cerebral palsy in 2022/23





professionals across the UK.

The amount we need to fundraise every year to provide this current level of service is

# £2 Million

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. Thank you to everyone who has supported us this year - we simply couldn't continue to make a difference without you!

# Better Start Ball 2023 raises almost £20,000 on World CP Day!

We would like to extend a huge thank you to everyone who attended our 'Better Start Ball' at the Parkgate Hotel on World Cerebral Palsy Day (6th October 2023).

Over 200 guests attended the event to help us raise almost £20,000 for 'Better Start, Better Future' in one evening.

We were delighted that our friends at Slater and Gordon Lawyers were able to offer their support as the headline sponsors for the evening, and we would like to thank Yvonne Agnew for speaking so highly of 'Better Start, Better Future' before introducing our short film.





It was fantastic to have our newest ambassador, Welsh Paralympic Athlete, Olivia Breen, attend the event. Not only was it the perfect way for us to welcome her into our Cerebral Palsy Cymru family by giving her the chance to meet our supporters and staff members, but it was also so inspiring for our guests to hear more from Olivia

during the Q&A section. This was hosted by Lowri Morgan, who is not only a Welsh television presenter but also an exceptional endurance adventurer and athlete.

You can read more about Olivia and her new role as a Cerebral Palsy Cymru ambassador on the next page. We are very much looking forward to working more closely with Olivia and Lowri in the future!



We were also delighted to welcome our good friend Nico Fitz to entertain our guests, as well as his colleagues from Mowgli Street Food Cardiff who, as announced on the night, have now raised a phenomenal £64,605 for us as their in-house charity.



Following on from Nico's rousing performance we hosted a live auction which had everyone bidding for exceptional lots kindly donated by Bluestone Wales, Bad Wolf and our good friend Henry Engelhardt.

Finally, the evening was rounded off by The Big What?! Band as our guests filled the dance floor to boogie the night away after helping us raise vital funds for children and families across Wales living with cerebral palsy.

We would also like to extend our warmest thanks to Kew Planning and Stokes Case Management for their sponsorship for our ball, helping to make it an incredible fundraiser for us.



# BREEN

## Paralympian Olivia Breen joins our team as our new Ambassador

Olivia, who was diagnosed with cerebral palsy at the age of two, has represented both Wales and Great Britain in the Commonwealth and Paralympic Games, winning Gold in Birmingham in 2022. She is a passionate and hands-on supporter of Cerebral Palsy Cymru, helping us to raise £22,220 in just seven days as part of our Big Give Christmas Challenge in 2022. Below, Olivia shares with us what it was like growing up with cerebral palsy and why it means so much to her to be an ambassador for Cerebral Palsy Cymru.

I was diagnosed with cerebral palsy (CP) at the age of two, and my parents tell me that the benefits of all the early years of therapy that I received made a massive difference to how I developed. Because having cerebral palsy is a part of who I am it's not something I think of very often - it is what it is! I have a mix of ataxic and athetoid CP which affects my balance and coordination and means that I move all the time.

When I was younger, my parents always encouraged me to try different sports just like my brothers who are also very sporty. I tried swimming, trampolining, dance and horse-riding and they all really helped my symptoms. I loved them all but running was the thing which made me really happy. I always found school really difficult but always loved PE and more practical lessons. Before my first sports day at infants school, my parents were really nervous about how I would get on because at that point I was still falling over all the time. They didn't need to worry though because I won my race and from then on, I knew that running was going to be my thing. I really loved the feeling of winning and being good at something.

The highlight of my career so far has to be the 2022 Commonwealth Games. I was made co-captain of the Welsh Athletics team for the Games and the team was the most special I have ever been on. It felt like family and we all really supported each other. I was the first athlete to compete on the track for Wales and I won. I literally couldn't believe it. To do that in front of a home crowd with all my family and friends around me and after the uncertainty of the COVID19 pandemic was like a dream come true. On top of this I was the first woman to win a gold medal on the track in 32 years. The year was topped off by me becoming BBC Wales Sports Personality of the Year. 2022 was definitely a year of highlights!

At the moment I am on the longlist of athletes who are likely to go to the Paralympic Games next year and I am determined to keep myself as fit and healthy as I possibly can and throw everything at my training.

If you are reading this and are thinking of taking up a sport, I would simply say try it! You never know where it might lead. If you don't like it then try a different sport until you find one you like. It's not just about medals, the health benefits of taking part in sport are immense both physically and mentally.





Growing up trying all different sports made a huge difference to my symptoms and also gave me confidence and focus. It is also really social and helps you to meet people and make friends. I always say take every opportunity which is offered to you. Disability Sport Wales is a great organisation and offers the opportunity to try all sorts of different sports and it's really fun aswell.

I am absolutely thrilled to be an ambassador for Cerebral Palsy Cymru and it was wonderful to visit their children's centre earlier this year to see the great work that they do. They are participating in the Big Give Christmas Challenge in a few weeks time which is an amazing campaign! Whatever donations are made during the campaign are doubled - wow, what a huge difference this could make! I would also urge anyone deciding which charity to support, to choose Cerebral Palsy Cymru. The difference which their therapy can make to babies who have or are suspected of having CP is phenomenal and the ongoing support of the charity to children with cerebral palsy and their families makes all the difference.

## Training and education courses at Cerebral Palsy Cymru

At Cerebral Palsy Cymru, we believe that sharing knowledge and skills is essential for the benefit of the children we see. In June and July this year, we hosted our 7th EiSMART Early Intervention & Assessment course at our specialist children's centre in Cardiff, sharing our world-leading expertise in the treatment of cerebral palsy with therapists from UK and Ireland.

Although primarily for therapists to enhance their skills, the EiSMART course also provides families of babies who have, or are at risk of having cerebral palsy, the opportunity to work alongside our expert therapists and the course participants to experience the benefits of intensive early intervention.

The practical sessions of the course are focused and individually tailored to the specific needs of every infant, mainly around promoting and encouraging early interaction, play, infant self-initiated movement, sleep or daily co-occupations such as feeding or dressing.





In the lead up to the practical sessions, our therapists work with local neonatal teams to identify families who will benefit from taking part in the practical sessions, often while they

are still in neonatal care. A number of the babies who have previously been selected to take part in the practical sessions for these courses have consequently either been referred or selfreferred to us to receive specialist therapy through our early intervention programme 'Better Start, Better Future'. Evan was one of these babies who participated in the recent practical sessions and who is currently receiving specialist early intervention therapy at Cerebral Palsy Cymru.

"Our son Evan was born at 26 weeks and unfortunately at 72 hours of life had medical complications relating to the blood supply to his brain which sadly is not uncommon in extremely preterm babies. This resulted in a weakness in Evan's left side of his body," explains Evan's mum, Lauren. "After finding out about Cerebral Palsy Cymru, I self-referred Evan and after an initial consultation, he is now regularly attending their children's centre for specialist early intervention therapy.





The progress of his left-hand side is incredible. Some examples are that he is now able to put both hands on his bottle, not just his right hand. Following the recent Ei SMART course, he is now able to put both feet on his pram bar. He can now also reach out and feel our faces with his left hand too.

The enhancements we've seen in his left-hand side are down to the extremely valuable early intervention techniques we've learned and which we work hard to put into practice at home. There was a time when we couldn't think too much about his future, what he was or wasn't going to be able to do but we are now very optimistic for his future and that is a wonderful feeling." Thirty one occupational therapists and physiotherapists attended the training, which provided an opportunity to develop their skills working with babies and their families in neonatal units and post discharge during the first year of life.

The first part of the course is delivered remotely, enabling professionals from across the UK to participate in the online education and learning seminars, which are delivered by expert guest speakers from the field of early intervention and which incorporate current scientific knowledge and the latest theoretical developments.

The second part of the course, hosted at our children's centre in Cardiff, consists of 3 days of intensive practical sessions. In these sessions, the course participants focus on translating their acquired knowledge into practical skills, working with babies and their families with guidance and support from the course tutors, including Cerebral Palsy Cymru's specialist therapists and Family Support Coordinator.



"It's hugely important for us to share our specialist expertise with colleagues from NHS teams, promoting excellence and best clinical practice for infants at high risk of cerebral palsy," explains Jenny Carroll, our Centre Director and Consultant Physiotherapist.

"Looking to the future, we plan to expand the training we offer to provide a wider range of training options for families as well as clinical professionals at every stage in their career development. Sharing our specialist knowledge and skills with the wider community and NHS teams in this way will help us to develop a new income stream to help fund our free early intervention service 'Better Start, Better Future', as well as meeting our ultimate goal to improve the quality of life of all children in Wales living with cerebral palsy."

To find out more about our upcoming courses, please visit: www.cerebralpalsycymru.org/for-professionals

Alternatively, please email **courses@cerebralpalsycymru.org** to find out more about the courses we offer and how they might benefit you.

# Because we know. Babies in the future will still need your help.

For over 31 years we have been dedicated to transforming the lives of children living with cerebral palsy and their families. We are the only specialist service of its kind in Wales with families often describing the impact that we make in their lives as 'life changing.' We also know that many families receive no other support, other than that from Cerebral Palsy Cymru.

We're not a charity that receives lots of legacies but when we do, these gifts, whatever the size, have been invaluable and have often enabled us to provide more support to more families who need us.

We know that around 70 babies are born each year who will have cerebral palsy. We want to make sure that no child and their family is left unsupported, now or in the future.

If you are thinking about writing or updating your Will, please do consider leaving a gift to Cerebral Palsy Cymru. Every gift – no matter the size – makes a difference. Even 1% (so those closest to you inherit 99%) or a modest sum of money will help provide for those babies yet to be born.



Leaving a gift in your Will to Cerebral Palsy Cymru is a straightforward process. All you need is our charity address and registered charity number. To download our free guide to leaving a gift in your Will to Cerebral Palsy Cymru please scan the QR code.

If you would like to chat about leaving a gift in your Will or to visit the centre to discuss doing so please contact Emma Brooks, Trusts & Legacies Fundraising Manager on 02920 522600 or email emmab@cerebralpalsycymru.org.

# Irwin Mitchell sponsor therapy room 7 at our children's centre



We are delighted that Irwin Mitchell have sponsored one of our therapy rooms at our children's centre.

It was wonderful to welcome Abigail Salter and Kieron Wilcox from Irwin Mitchell's Cardiff office to our children's centre earlier in September to celebrate the partnership. Whilst they were with us, they even got stuck in and helped our fundraising team with some tasks!

The sponsorship of therapy room 7 will help us ensure that we can continue to provide life-changing therapy and support from our new home to children and families across Wales living with cerebral palsy. We have been delivering specialist therapy from our new children's centre since May 2021, and it is always a positive highlight for us when we have the opportunity to showcase to our supporters the vital impact that we are making every day to the families who visit us for therapy and early intervention.

Room 7 not only acts as a therapy room but is also part of a group of rooms that can be opened up to facilitate specialist and tailored group therapy activities such as our 'Jungle Explorers' project and 'ESCAPADES!', both of which are kindly funded by BBC Children in Need.

"Irwin Mitchell is proud to support Cerebral Palsy Cymru and the fantastic work it does to provide support to children with cerebral palsy and their families in Wales," says Abbie, a medical negligence lawyer at Irwin Mitchell. "We understand the valuable impact that access to these services has for children and their families."



Marie Wood, Director of Fundraising & Communications at Cerebral Palsy Cymru adds: "We very much welcome the opportunity to engage with new corporate supporters and it has been wonderful to get to know the Irwin Mitchell Cardiff team. They will also be helping us to celebrate Cerebral Palsy Awareness Month in March by offering sponsorship support for our awareness and fundraising activities, and we look forward to working with them over the coming year."

If you're a business or know of a business, of any size, who has a passionate team who are keen to make a difference, we would love to hear from you! There are a huge number of ways that you can get involved including charity of the year partnerships, attending and engaging with our events and campaigns, sponsorship, volunteering and much more. For more information, please email Marie Wood on mariew@cerebralpalsycymru.org

## The National Lottery Community Fund helps fund 'Better Start, Better Future.'

We are delighted to have been awarded a grant from The National Lottery Community Fund Wales which, over the next four years, will help fund 'Better Start, Better Future'.

For babies at risk of cerebral palsy, time is of the essence as the plasticity of the brain is at its greatest in the first two years of life, which is when our specialist therapy and family support can make the greatest impact on their future outcomes.

Last year we experienced an unprecedented number of referrals of babies to this service, who had or were at high risk of having cerebral palsy, so

the funding will help to make sure that no baby or family is left unsupported.

Better Start, Better Future is a free service for every family that needs it and is fully reliant on charitable donations from organisations, and supporters like you. We still need to fundraise to fully fund the service this year.

The Lottery funding will also enable us to employ a part-time Clinical Psychologist to increase the depth of support that we can offer children and families.

We would like to say a big thank you to The National Lottery Community Fund Wales and all the National Lottery players!



## NFU Mutual Llandeilo go the extra mile for Cerebral Palsy Cymru

At the start of the year we had a wonderful email from the team at the Llandeilo branch of NFU Mutual explaining that they would like to offer their support during 2023. The team, led by Gerwyn Davies, explained that they had an exciting year of fundraising planned and had been inspired to support us because one of their team members, Rebecca, has a daughter who has cerebral palsy and has received support from us.

"The therapy Alys received was fantastic," said Rebecca, Alys' mum. "I felt like Dawn and Helen just got Alys so quickly and were able to instantaneously adapt her therapy into a way that made Alys comfortable and engaged. They got the most out of her in the sessions and I cannot recommend the therapy team enough, which is why I was thrilled when we adopted Cerebral Palsy Cymru as our charity for this year."



The team have worked tirelessly in their fundraising efforts, with a grand summer ball for 300 guests at the beautiful Green Grove near Llandeilo. Alongside this, Gerwyn, with two friends, Ralph Priller and Huw Davies, took on the gruelling Lands' End to John O Groats cycle challenge back in August.

Their efforts paid off enormously and we're thrilled that the team have raised a phenomenal £30,000 during the year. We would like to send our warmest thanks to the team and also to their kind sponsors, the local Llandeilo community and their supporters who have embraced their challenges whole heartedly.



# GET BAKING NEXT MAY & HELP US RAISE SOME DOUGH!

Roll up your sleeves and fire up the ovens next year to help us make a difference to children and families across Wales living with cerebral palsy.



We are looking for schools, community clubs, businesses, workplaces and families to get baking for us in May 2024 to help us make Cake & Tea for CP 2024 the biggest and best yet!

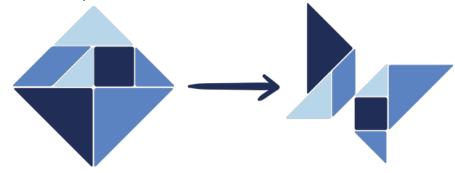


If you would like to sign up, or if you want more infomation, please email Rose Skinner roses@cerebralpalsycymru.org or scan the QR code to complete a short form and we will get back to you!

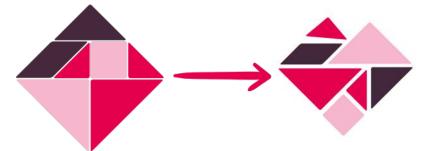
## What is 'The Tangram'?

Our newsletter is called 'The Tangram' and you might be wondering why!

The Tangram is actually a Chinese geometrical puzzle consisting of a square cut into seven pieces which can be arranged to make various other shapes.



What does this have to do with Cerebral Palsy Cymru we hear you say? Our logo is infact a tangram made into the shape of a heart.



This unique design was chosen for our logo as the different shapes within the tangram represent the individual characteristics that make us who we are - in one singular form they all lock together to make a square but can also be rearranged to create uniquely different shapes and forms. If you look closely, you can see that the triangle at the top of our logo is slightly out of alignment which is a reminder that no-one is ever perfect, and that is ok!

Why not have a go at making your own Tangram Christmas decoration? Follow the instructions on the opposite page to make a fabulously festive creation! **Step 1** - Cut the shapes out (ask an adult to help you!)

**Step 2** - Arrange them into a festive pattern! We've provided a Christmas tree example opposite but there are plenty more examples to choose from online.

**Step 3** - Stick your shapes onto a white paper plate.

**Step 4** - Once dry, use a hole punch to create a hole at the top of the plate and thread some tinsel or ribbon through it.

**Step 5** - Hang your tangram Christmas decoration in your home!



Send us a photo of your Christmas creation! Email fundraising@cerebralpalsycymru.org or whatsapp it to us on 07939516112



# 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



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