

# THE TANGRAM

SUMMER 2024

Sponsored by



Case  
Management  
Cymru



**CEREBRAL  
PALSY** CYMRU

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



# FAMILY FUN FIESTA

## with Cerebral Palsy Cymru

**Saturday 21st September | 14:00 - 16:30**

*Join us at our children's centre for an afternoon of singing, dressing up, creativity, food and fun!*

Children aged 2 and under **FREE**

Children & adults **£3 each**

Family ticket (2 adults & 2 children) **£10**

To find out more, or to purchase your tickets, please scan the QR code or email [fundraising@cerebralpalsycymru.org](mailto:fundraising@cerebralpalsycymru.org)

Sponsored by:

**IM** irwinmitchell



### Dear Friends,

Hello and welcome to our latest edition of The Tangram, which is kindly sponsored by Case Management Cymru.

Since the start of this year, we have been working closely alongside the team at Case Management Cymru as we develop our private therapy service for children, young people and adults living with cerebral palsy.

Our new service offers families and individuals the choice to access our specialist services after they graduate from our free early intervention programme, *Better Start, Better Future*, if they do not have a referral made by their local health board. We are so grateful to the staff at Case Management Cymru for their expert advice and insight, and for their ongoing support. More details about this service can be found further on in this newsletter.

As you will see on the next page, we deliver our services to families right across Wales. The figures show another unprecedented year of growth in referrals for *Better Start, Better Future*, and we know from parent feedback that our specialist therapy and support continues to make a huge difference to families.

It was a privilege to share our impact, as well as highlight our need for investment to sustain these vital services, to MSs at our awareness event at The Senedd that took place during Cerebral Palsy Awareness Month in March.



As the demand for our specialist services increases year on year, like many charities, we face significant financial challenges.

We were deeply saddened to hear the news of the closure of the Bobath Centre, Watford last month, and we will work together, as a community and with Welsh Government, to ensure that we can protect our specialist services for children and families in Wales.

More than ever, we will be reliant on the generosity and friendship of all our families and supporters. Please visit our website, or get in touch, to find out about upcoming events and for information about various ways you can get involved in our fundraising activities.

Thank you for being a valued part of the Cerebral Palsy Cymru family and for your continued support.

**Jenny Carroll**  
Centre Director and Consultant Physiotherapist.



## Our year 2023/24 in numbers

We are Cerebral Palsy Cymru.

We are a national centre of excellence and the only specialist cerebral palsy charity in Wales.

We are internationally recognised for our specialist therapy and are proud to have families at the heart of everything we do.

Cerebral palsy is the most common physical disability in children worldwide, and it is estimated that every 5 days a baby will be born in Wales who will have the condition.

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

# 1,121

specialist therapy sessions delivered by our team of 15 therapists



Our therapy team treated children and supported families from across all 7 health boards in Wales



# 301

babies and children across Wales received our specialist therapy and support

# 87

new babies were referred to our specialist early intervention service, *Better Start, Better Future*

The age of the youngest baby we saw at their initial consultation was  
**2 weeks**  
(corrected age)

# 11

'Better Start Together' play groups were facilitated by our family support team



# 73

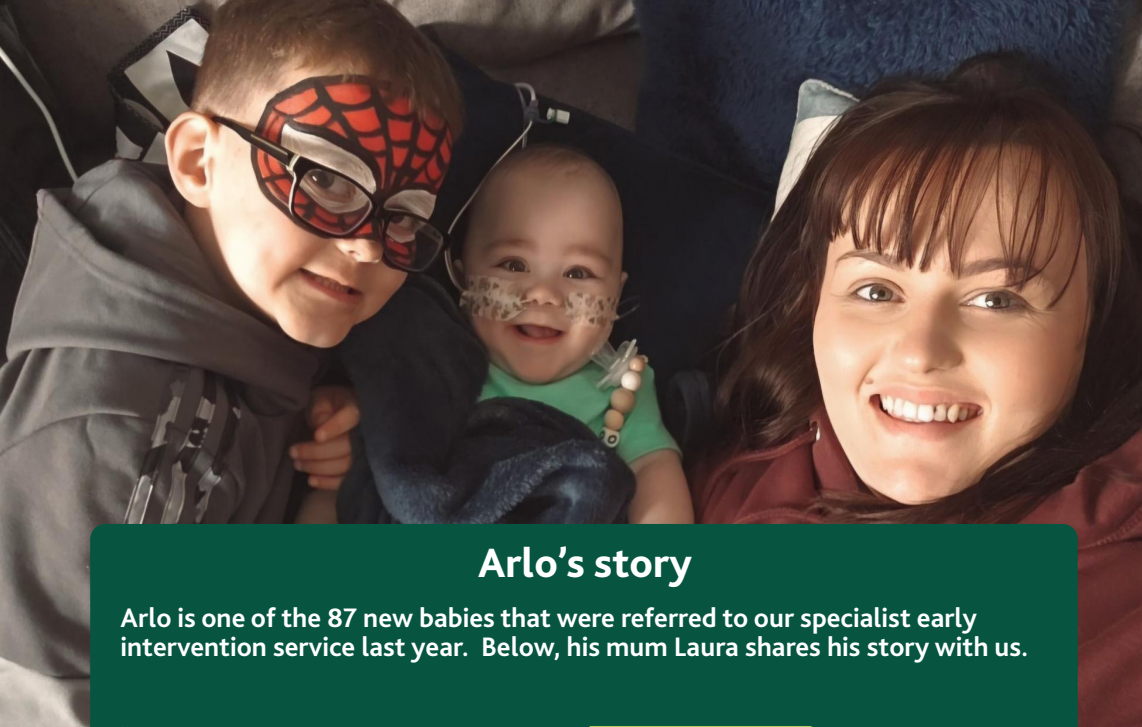
family support sessions took place, providing much needed emotional, practical and mental health support to our families

**98%** of families surveyed rated their satisfaction with our therapy sessions as 8-10/10

**100%** of families surveyed said that our specialist therapy and support has helped them address concerns brought to their sessions







## Arlo's story

Arlo is one of the 87 new babies that were referred to our specialist early intervention service last year. Below, his mum Laura shares his story with us.

"We first heard about Cerebral Palsy Cymru whilst Arlo was on the Neonatal Unit at the University Hospital of Wales. Several of our consultants had advised us to self-refer Arlo to the charity's specialist early intervention programme *Better Start, Better Future* to help give Arlo the best possible start in life.

We decided to call our son 'Arlo' after Disney's 'The Good Dinosaur' as it fits with what we were hoping for our boy after my waters ruptured at 23 weeks gestation – that he may be born into the world small but grow into a strong, healthy boy.

I went into labour at 26 weeks, and I remember being rushed down to theatre. Arlo was born not long after that, weighing a tiny 960g.

To hear the smallest little cry from someone so small is something that I simply cannot put into words.



Arlo was then taken to the Neonatal Unit and put on a ventilator. I waited hours to see him and when I was eventually wheeled up to the unit, he was on 100% oxygen and nitric oxide. In the following days, weeks and months on the unit several of his health issues came to light. He developed a grade 4 IVH, a large PDA, metabolic disease and chronic lung disease, as well as treated for sepsis meningitis.

Following discharge, the neonatal outreach team came to do a routine head circumference and found Arlo's head had grown bigger than normal and following a scan we found he had developed hydrocephalus. Arlo was admitted as a medical emergency where he underwent brain surgery to have a VP shunt fitted to help drain fluid from his brain.

Since this has happened, Arlo now has been diagnosed with global development delay. We are unable to give him any fluids or solids orally, as he can't swallow safely. He is on the waiting list for a peg to be fitted, and is fed continuously as he's unable to tolerate large volumes. He also requires a suction machine due to increased secretions, where his speech and language team have advised that the signals aren't being sent down from his brain. He is also under ophthalmology and is being checked for cortical visual impairment. Due to the extent of the grade 4 IVH and hydrocephalus, they believe the pathway between his eyes and brain have been damaged.



He also has low muscle tone, and a referral has been sent to the wheelchair services for an adapted pram to help his posture.

**We feel as time is progressing, his issues are starting to come to light, but he is the happiest little human.**

Our first session at Cerebral Palsy Cymru was such an eye opener. There were so many happy, smiling faces that greeted you as soon as you walk in who genuinely just want to help. We learnt so many new things to try with Arlo in our first session alone such as handling and movement.







Thanks to *Better Start, Better Future* Arlo has progressed so much. He is now able to tolerate tummy time a little better and is interacting with us more – it was actually the physiotherapy team at Cerebral Palsy Cymru that picked up on his irregular eye movement and referred us to see ophthalmology.

**Better Start, Better Future** has helped us as a family to be more positive and has helped us explore different physiotherapy techniques so we can help Arlo the best we can.

For Arlo to be chosen to represent the babies currently accessing Better Start, Better Future for the official opening of Cerebral Palsy Cymru's children's centre was such an honour. It was a pleasure to meet HRH The Duchess of Gloucester and it meant so much for Eluned Morgan, Minister for Health and Social Services of Wales, to mention Arlo and the importance of early intervention in her speech. Arlo was the star of the show, and so many people came over to see him! It was a pleasure to be a part of the day.

Finally, my husband and I would like to thank the whole team at Cerebral Palsy Cymru from the bottom of our hearts for all the love and support that you have shown us. **You were the light that we needed at a dark time in our lives.**



 **Better start  
Better future**

## Our Family Support Service

Alongside our specialist therapy, we also offer a vital Family Support Service which provides practical, emotional and mental health support free of charge for families that need it.

**Having a child with cerebral palsy affects the whole family.**

Classed as 'vulnerable' these families are at higher risk of mental health difficulties.

Access to our Family Support Service right from the start, supports and empowers the family, reducing the level of trauma and stress they experience.

When families first contact us, they are often still recovering from birth trauma, trying to cope as a new parent and with the fact their child may have a disability. They often know little about cerebral palsy and feel hopeless. Families experience emotional issues such as guilt, anxiety, depression, PTSD, feel isolated and sometimes express feeling close to breaking point.

**Our Family Support Service is currently offered free of charge to every family that needs it and is the first point of contact for new families referred to us. It also:**

- Provides families access to 1:1 support with an experienced parent counsellor and clinical psychologist
- Supports families during their child's initial therapy sessions
- Offers ongoing support to families either face-to-face, or over the phone
- Reduces parent isolation through our monthly playgroup



In our Annual Family Support Survey, when families were asked what their greatest need was, 58% said they needed emotional support and 42% said they needed support with their mental health. In 2023/24, 61% of families said they hadn't received any emotional support for their family from anywhere else other than Cerebral Palsy Cymru.



"When we stumbled across your service we were in a very dark place as a family. We didn't think anyone could support us the way we needed, every day was a struggle.

There was little hope and life seemed to be unravelling. You will never know how important that first meeting was for us...it changed everything.

You listened and you made me feel like I wasn't alone. You offered the help that we so desperately needed. Today those results speak for themselves. Noah is thriving, our family is healing, and our future is bright."





## Because we know. Your future gift will help those babies yet to be born.

### Why might I leave a gift in my Will to Cerebral Palsy Cymru?

We are the only specialist charity of its kind in Wales, with families often describing the impact that we make as 'life changing'. We are a lifeline for families, who are often trying to cope after a traumatic birth, and as new parents, as well as coming to terms with the fact that their baby might have a disability. We work alongside families, providing specialist therapy for their child and emotional and practical support for the whole family.

As a charity, we depend on fundraising activities, donations, and gifts in Wills for 83% of what we need to fund our vital work, with only 17% coming from statutory sources. We know that around 70 babies are born each year in Wales who will have cerebral palsy and we want to make sure that no child and their family is left unsupported, now or in the future.



### Does it need to be a big gift?

No, every gift – no matter what the size – makes a difference. Even leaving 1% of your estate (so your family and those closest to you inherit 99%) or a modest sum of money will help provide support for babies like Arlo, whose story features in this newsletter.

### What difference would my gift make?

Previous gifts in Wills have helped us to launch our specialist early intervention service for babies, enabled us to see more children and families who need us, and, in these challenging times, they will make sure that we are here long into the future to help those babies yet to be born.

### Are there any benefits to leaving a gift in my Will?

Yes, aside from the lasting impact you will make, leaving a gift in your Will to charity can eliminate or reduce the Inheritance Tax payable on your estate. Your solicitor will be able to explain how the Inheritance Tax rules apply to you and your particular circumstances.

### What can I do now?

Read our free guide to leaving a gift in your Will by scanning the QR code opposite.



Have a chat about leaving a gift in your Will with Emma Brooks our Trusts & Legacies Fundraising Manager on 02920 522600 or email [emmab@cerebralpalsycymru.org](mailto:emmab@cerebralpalsycymru.org)

Make a pledge or let us know that you will be leaving a gift in your Will to Cerebral Palsy Cymru.

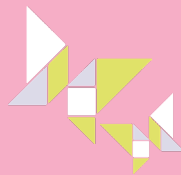
Talk to a Wills advisor/solicitor. If you are thinking about writing or updating your Will, please do consider leaving a gift to Cerebral Palsy Cymru. All you need is our charity address and registered charity number.

Thank you for taking time to consider this.





# A royal visit to officially open our children's centre



We were delighted to welcome our Royal Patron, HRH The Duchess of Gloucester, to officially open our new children's centre in April.

Thanks to support from the Welsh Government, The Moondance Foundation and other corporate and philanthropic donors, we were able to purchase and transform our new building into a national centre of excellence that provides world-leading treatment of cerebral palsy to hundreds of families and children across Wales every year.



Our children's centre first opened its doors in May 2021, in the midst of the COVID-19 pandemic. Since then, over 800 families from across Wales have walked through our doors to receive our specialist therapy for their children.

Now that the renovation work is officially complete, we were thrilled to receive a visit from HRH The Duchess of Gloucester, who has been our much-loved patron since 1996, on Wednesday 24th April to officially open our children's centre.

Alongside meeting a number of supporters who contributed to our 'Build a Better Future' capital appeal, which helped fund the second phase of development, the Duchess met with families who have received life-changing therapy and support from us, like baby Arlo whose story you read earlier.



Also in attendance was Julie Morgan MS, who has been an energetic supporter of Cerebral Palsy Cymru for several years, and The Baroness Morgan of Ely, Cabinet Secretary for Health and Social Care, Eluned Morgan, who said:

"It was a privilege to attend today's event and see first-hand how this building has been transformed into a specialist children's centre that makes a hugely positive impact on the lives of so many families across Wales. It was wonderful to have the opportunity to meet some of the families who have benefited from this charity's services, as well as the staff and volunteers who work tirelessly to ensure that families living with cerebral palsy across Wales can access the specialist therapy and support that they need. I also want to pass on my thanks to all the people who have contributed generously to support the charity."

We would like to thank everyone who attended the official opening of our building and all who have helped us to secure and develop our new home.







## Celebrating the success of the Cwm Crafters on raising £90,000!

Meet Sue Jones, our wonderful volunteer ambassador who, with the help of her fundraising group the Cwm Crafters, has raised over £90,000 for Cerebral Palsy Cymru!

Sue began her volunteering journey with us 16 years ago, when her cousin's son, Tomos, was diagnosed with cerebral palsy and started receiving specialist therapy and support at our children's centre.

After visiting our centre in 2008 to attend one of Tomos's therapy sessions, Sue started knitting chicks and bunnies for our Easter Knitting Appeal which was taking place at that time. She then dedicated time to selling these knitted goods in her community in Aberdare and the surrounding areas in Rhondda Cynon Taf.

The following year, Sue decided to combine forces with other knitters in the local community to sell knitted and crocheted items at King Charles Hospital in Merthyr, and established the Cwm Crafters fundraising group.

Their exceptional knitting has not only helped raise vital funds for us, but it has also done so much to raise awareness of Cerebral Palsy Cymru and the services we provide.

Over the years, Sue has continued to make and nurture new community connections to help support our fundraising efforts including supermarket community champions, local church groups and weight-watchers groups, alongside providing us with support for our fundraising appeals and events.



She also has a monthly stall at Cwm Cynon hospital, has organised welly walks and bucket collections and regularly volunteers at our Christmas markets!

It was wonderful for us to invite Sue to our children's centre earlier this year to personally thank her for her phenomenal fundraising efforts over the past 16 years. We would also like to take this opportunity to thank all those involved with the Cwm Crafters - your creative knitting and tireless fundraising has helped make a huge difference to children and families across Wales living with cerebral palsy - diolch yn fawr iawn i chi gyd!

Feeling inspired and thinking of setting up your own fundraising group? Get in touch with our fundraising team on **02920 522 600** or send us an email to discuss your ideas! We would love to hear from you!

## Thoughts from our therapists

Kirsty Taylor, our Clinical Specialist Physiotherapist, reflects on her time at the 2024 EACD Conference in Bruges.

This year's European Academy of Childhood-onset Disability (EACD) conference was the 36th meeting for the association and brought together healthcare professionals, researchers and families from across the globe.

The central theme of the 2024 conference was 'composing a new symphony', inviting participants to explore innovative research and build new connections by embracing positive thinking, taking responsibility, and reshaping plans to meet the needs of an ever-changing world.

I was delighted to be given the opportunity to go to the conference this year alongside my colleagues from Cerebral Palsy Cymru. As well as being a Clinical Specialist Physiotherapist, I am a member of EACD's Families and Users' Forum (FUF), representing siblings as my twin brother, Simon, has cerebral palsy.



At the conference, several of my colleagues delivered poster presentations to share the impact of the work we have been doing at Cerebral Palsy Cymru through various projects including 'Escapades!', 'Jungle Explorers', and our specialist early intervention service *Better Start, Better Future*. The team also had a chance to showcase the collaborative work we have been doing with the Cerebral Palsy Register for Wales and Cerebral Palsy Youth Voice Wales. I'd like to take this opportunity to say a huge well done to Helen, Marissa, Rachel, Sally, and in particular Gosia and Jenny who also took part in symposiums on early intervention and clinical decision making.

The opportunity to present our work, and network with EACD members throughout the conference, enabled us to develop links and learn from families and other professionals from all over the world which is hugely beneficial in helping us to optimise the services that we offer to our families at Cerebral Palsy Cymru.





Aside from supporting my colleagues, I attended many presentations and talked to researchers around using powered mobility for infants who are likely to need additional support to move around by themselves, learning that *"it's not just about learning to drive but driving to learn."*

This helped me to focus my thoughts and ideas prior to the launch of our own early mobility group, 'Let's Move Together' which starts later this month.

I was also very excited to meet other members of the Families and Users' Forum (in person rather than on a screen!) at the conference. It was wonderful to get to know them better and continue our discussions around how we can further increase the involvement of families in research and the development of guidelines, for example for early intervention. I felt really proud to be part of such an inspirational group of people, both as part of the team at Cerebral Palsy Cymru and across the EACD network.

My personal highlight of the conference was the huge effort the organisers made to put families and those with lived experience of disability at the heart of all that we are trying to achieve.



This was beautifully encapsulated by the striking performance of a young girl moving gracefully around the stage in her powered wheelchair before being raised up by dancing children in the Opening Concert.

What also resonated strongly with me during the conference were the views and suggestions from parents and people with lived experience of disability, on how to promote shared engagement with trust, patience and respect for their unique situation. I also appreciated the clear passion of everyone I spoke to, to provide timely support and help to empower parents and people living with disability now and for the future, and the reminder that we should consider their choices and preferences in helping to make interventions targeted and relevant throughout the lifespan.

I feel that the messages that I took home from the conference are closely aligned with our values here at Cerebral Palsy Cymru. As a charity that was set up by a group of founding parents, we recognise the importance of building relationships with families, sharing relevant knowledge and making joint decisions, and ensuring our interventions are meaningful to the child or young adult. As one of the speakers at the conference eloquently summarised; *"we all want to live a good life today, tomorrow and in the future!"*

**'Let's Move Together'** is a new early mobility play group for children age 6 month - 3 years. The aim of the group is to give young children who are likely to need additional support to move, the chance to explore, play and interact in a fun environment. For more information please email [info@cerebralpalsycymru.org](mailto:info@cerebralpalsycymru.org)



## Meet Rowan, our new Volunteer Coordinator!

(Left to right: Joanna (HR & Volunteers Manager), Andrew (Volunteer), Lauren (Shop Manager), Tom (Volunteer), Rowan (Volunteer Coordinator) )

We are delighted to have been awarded a Volunteering Wales Main Grant, administered by the WCVA on behalf of the Welsh Government, which has enabled us to employ a part-time Volunteer Coordinator to help us recruit more volunteers, the lifeblood of our four charity shops, and to ensure that our volunteers get the best possible experience while at Cerebral Palsy Cymru.

In between delivering hampers to our shops to celebrate Volunteers Week to thank our wonderful volunteers, we sat down for a chat with Rowan, our new Volunteer Coordinator, to find out more about their new role and volunteering at Cerebral Palsy Cymru.

### Why are volunteers so important to Cerebral Palsy Cymru?

Volunteers are so important to Cerebral Palsy Cymru because we simply wouldn't exist without them.

From the start of our charity's journey, the generosity of our supporters has allowed us to grow. Volunteers give us their time, they offer a friendly face in our shops, they help us at events, and all while asking for nothing in return. They set an amazing example of kindness and are a part of the heart and soul of Cerebral Palsy Cymru.

### Do you have to commit a certain amount of hours to volunteering every week?

The wonderful thing about volunteering is that you can give as much of your time as you want, no amount is too big or too small! We appreciate any amount of time that you can spare, and we are happy to work with all of our volunteers to suit their needs.

### What sort of opportunities are there available at Cerebral Palsy Cymru?

There are so many to choose from! From working on the tills or sorting through donations in our charity shops,

volunteering at our children's centre with administrative tasks, or helping our fundraising team at events, there is something for everyone.

### Q. What would you like to say to someone reading this who is thinking about volunteering?

If you are thinking about volunteering, my best advice is to just give it a go! Simply scan the QR code below to complete a short form or call 02920 522 600 for a friendly and informal chat about our current volunteering opportunities. In my experience, volunteering is so rewarding, not only because you are donating your time to help others, but also because there is so much to be gained from volunteering, such as work skills, job references, lasting friendships and a sense of community.



## Spotlight on our corporate supporters: Case Management Cymru



Case Management Cymru delivers specialist case management to adults and children with acquired brain injury, a spinal or orthopaedic injury, birth injuries and learning difficulties. The team at Case Management Cymru have been hugely supportive in assisting us with the launch of our new private therapy service. Below, Kat Jones from Case Management Cymru shares more about our partnership and how case managers can assist families living with cerebral palsy.

"Hello, I'm Kat and I'm the Marketing and Events Officer at Case Management Cymru. My role involves helping to promote Case Management Cymru at different events, as well as managing their social media, press opportunities and partnerships, like the one we have with Cerebral Palsy Cymru.

The role of a Case Manager is very varied and totally different depending on the needs of the individual client. Every Case Manager is there to guide and advise the client and their families through their journey, encouraging and supporting them to achieve their personal goals by helping them to access the right therapists, organisations, support and care. Each one of our case managers has a different area of expertise, but all have specific knowledge of the sector and services provided locally to South Wales.

We have a number of clients that have benefited from the support of Cerebral Palsy Cymru. We are thrilled to be supporting this charity and feel that it is an excellent opportunity for case managers to be able to refer their clients to such an experienced team of specialists.

We were delighted to support the launch event of Cerebral Palsy Cymru's private therapy service as we feel that this is a much-needed service in Wales.



We feel strongly that case managers will be able to refer into the service and that it will be incredibly beneficial for clients and families as it will provide children and young people with continued care as they grow.

We were delighted to have had an in-depth tour of the facilities and a chance to talk to the team at Cerebral Palsy Cymru, to better understand the new therapy service but also how we can help to promote it. It was also an excellent opportunity for us to network with other professionals and colleagues from across the sector, helping us to work together and collaborate. We are looking forward to becoming long-term supporters of Cerebral Palsy Cymru. The charity is very close to our hearts, and we are passionate about its goals and objectives."

If you know or work for a business who might be interested in partnering with Cerebral Palsy Cymru please email Carwyn Williams, Head of Corporate Partnerships on: [carwynw@cerebralpalsycymru.org](mailto:carwynw@cerebralpalsycymru.org)



### Introducing our private therapy service

Our private therapy service offers personalised therapy for babies, children, young people and adults living with cerebral palsy.

All our therapy sessions are conducted by one of our highly specialist therapists who have extensive experience working with children and young people living with cerebral palsy.

Therapy sessions take place at our specialist children's centre in Cardiff. We also offer virtual therapy sessions for those who are unable to travel to our therapy centre. Domiciliary visits may also be possible.

To find out more about our private therapy service, or to complete an enquiry form to express your interest and discuss your needs with a member of our therapy team, please scan the QR codes below or email [info@cerebralpalsycymru.org](mailto:info@cerebralpalsycymru.org)



Find out more

Enquiry form







We warmly invite you to join us at our

# BETTER START BALL

Friday 18th October



7pm till 12am

Enjoy a glamorous evening with dinner and entertainment at the Parkgate Hotel, Cardiff, in the company of special guests – all to raise vital funds for our specialist early intervention service 'Better Start, Better Future', which provides therapy and support for babies across Wales who have or are at high risk of having cerebral palsy.

**Tickets: £80pp or £800 for a table of 10**

To book individual tickets or to find out more, please visit  
[www.cerebralpalsycymru.org/events](http://www.cerebralpalsycymru.org/events)

For table bookings, please contact a member of our team on 02920 522600 or email  
[fundraising@cerebralpalsycymru.org](mailto:fundraising@cerebralpalsycymru.org)



Registered charity number: 1010183

Headline sponsor:

