

# NEWSLETTER

**My name is Karen,  
I have a son Jack who  
is two and a half and  
he has cerebral palsy.**

“ Jack has an older brother David; they go to nursery three days a week and love it there. Jack is amazing - a little ball of sass with a big personality and incredibly determined. He lights up a room and melts your heart with his huge giggle - he is just amazing.

Jack was born having seizures which were picked up on day five; he was having hundreds per day. We were advised that Jack would need surgery to disconnect one half of his brain in order to stop the seizures.

But part of disconnecting the right side of his brain meant there would be a deficit on the left side of his body. Jack has hemiplegia, meaning his cerebral palsy affects the left side of his body.

It's easy to forget just how massively Jack's cerebral palsy impacts him as we've never known him without but there's a lot Jack can't do, especially things we take for granted daily. We class Jack as pre-verbal because he says a few words but not consistently and only a few single words.

But he absolutely gets his point across - he points, he makes noises, he signs, he shakes his head and he says what he wants without the words!

We initially came to Cerebral Palsy Scotland through the CP Connect sessions. The sessions were totally different to anything else that we'd attended. I remember Jack just being happy and giggling through the sessions. It didn't feel like 'therapy', it felt like having fun with the therapists we quickly called friends.



We also came to Cerebral Palsy Scotland's fortnightly Baby buds group for a long time. Baby buds was really important to us at



the time. Especially with it being during Covid when Jack was born, and then how hectic Jack's life was, we had never really made it to any baby groups. And I suppose you worry where your child fits in at baby groups when they've got additional needs - too big for the baby group, not quite toddling for the toddler group.

For us it was one of the first groups that we'd been to where both Jack and I could be around other kids that were similar to Jack. It's nice to be at a group where there's no judgement; all kids are different, and everyone's progressing at their own rate. The kids are making physical progress but at the same time you're singing nursery rhymes, doing actions, having fun and chatting away. We really looked forward to the group.

**Continues inside...**



For me, it was nice to be in an environment where you could talk to other parents about struggles you face that other parents don't have.

**Yeah, it's just space to breathe and ask questions. It was just really vital for my mental health at the time.**

Jack left Baby buds when he turned two. But towards the end of last year I felt like we were in a place where we just needed some support. Jack's sleep is rough at best and life as a working parent-carer gets so heavy sometimes you just need someone to drag you out of a bit of a lull.

I felt Jack was kind of stagnating. We were all at one of the lowest lows that comes with the additional needs lifestyle so I reached back out to Cerebral Palsy Scotland and we were given therapy sessions at the start of 2023.

The sessions were amazing. Jack was so happy in the sessions - he was so willing. It was the most we'd seen Jack participate and it was the best we had seen his abilities show.

Before the therapy, we also really struggled with knowing if Jack understood us. There was no communication, which is an incredibly hard situation to be in. Knowing your child wants or needs something but no idea what.

But, during therapy Jack started pointing and making choices. We continued that at home and now Jack makes choices, be it picking a toy or food. It was a massive turning point for us. During the sessions we also started Makaton with Jack, something we'd never explored before. It's given Jack a voice, it gave Jack communication, it gave him a drive.

The sessions made a massive difference to not just Jack but us as well. Although Jack is the main focus, we were at a really low point. We were struggling to work out what we could do to support Jack and it's a horrible feeling, knowing that your child needs support and that you maybe aren't in the best place at that time to give them it.

Since then we've felt a lot better. For me going to the sessions was a bit of a boost and a pick me up. It inspires you to keep going. When you see progress and when you know you've got things you can do that can support your child, it gives you a different outlook. Without it, who knows how or when we would have got that boost that gave us a clear head and mindset and a focus for Jack?

We don't have milestones with Jack - we celebrate every inch-stone instead. It's everything that other people take for granted. That's a big deal to us and we've seen so many since the sessions.

**Our journey's been mad, it's been chaotic, and I don't doubt it always will be. But having a charity at our side who are there to support us as a family, not just Jack - it makes more of a difference than you could imagine.**



Save the date

Christmas Challenge

Big Give

28 November to 5 December

## Big Give Christmas Challenge

This year we're taking part in the Big Give #ChristmasChallenge. We need your help to fund a specialist therapist so we can reach more people like Jack and his family with cerebral palsy. Donations made during the campaign week will be doubled. Save the date and look out for more information on our social channels. One donation, twice the impact!



## Walk'n'Roll

In March we had people from all across Scotland taking part in our first ever virtual fundraiser. Each person set themselves a challenge for the month and we loved seeing the different ways people got moving. Together our fantastic Walk 'n' Rollers raised **£7,883!**

**This completely accessible event will be back in March 2024.**



## Policy update

We're ambitious for people with cerebral palsy and continue to advocate with government and policymakers for the cerebral palsy community to have life-long access to knowledgeable, compassionate services and support. With the Scottish Parliament currently on recess, we want to take the opportunity to highlight some recent work that our CEO, Stephanie Fraser has been doing to press for change.

Stephanie has met the new Minister for Public Health and Women's Health, Jenny Minto MSP, to inform of the biggest challenges people with cerebral palsy face.

We have also been in contact with Dr Una MacFadyen, Lead Clinician for the Children with Exceptional Healthcare Needs Managed Clinical Network, regarding how Cerebral Palsy Scotland can support their network with developments.

We continue to share important information with the cerebral palsy community including how to contribute to the design of the new National Care Service and requests to share your experiences with the Scottish Covid-19 enquiry. We also submitted a response to the Scottish Covid-19 enquiry in consultation with the community.

Make sure you receive these updates by signing up to our email list.

We will continue to monitor policy debates and developments across the UK as we continue to work to prioritise cerebral palsy in government agendas. Follow our social channels for more information.



## Supporter spotlight

# Christine Poole

**We want to shine a spotlight on a fantastic supporter who has gone above and beyond this year to help improve the lives of people with cerebral palsy in Scotland.**

Christine Poole got in contact with us in January to take part in the Glasgow Kiltwalk. By May, Christine had raised a phenomenal £12,240. Not only did a team of eight walkers come together as 'Team Arlo' and take on the Glasgow Kiltwalk in honour of Christine's wee boy Arlo, but Christine organised a charity football match in her local village and a coffee and cake morning at work. Thank you so much to Christine and Team Arlo for their truly incredible efforts.

Hear from Christine about her experience fundraising for Cerebral Palsy Scotland...

### How did you find out about Cerebral Palsy Scotland?

After receiving my son Arlo's diagnosis when he was six months old I was doing a lot of online research to learn as much as I could about the condition. I had heard of CP before but had no idea how varying the symptoms could be from person to person. Most of the information I was finding was coming from American organisations; then one day I stumbled across the Cerebral Palsy Scotland website where



they were promoting their annual conference, I signed up right away and have attended every one since.

### What inspired you to fundraise?

I was looking for something that I could do with friends and family that would also include Arlo in some way, when I saw the walk I thought not only would it be a fun thing to do, but it would help raise money at the same time.

Continues... 



### How would you sum up your fundraising experience?

We had great fun fundraising!

We organised a community charity football game, hosted work lunches, we had games, lots of cake and Hester from Cerebral Palsy Scotland came along and talked to us all about Cerebral Palsy Scotland which was really lovely. The support from our community, colleagues, friends and family was just incredible!

I would not hesitate to do it again or help someone else with their fundraising!

### What advice would you give other people thinking about fundraising?

Do it, it's definitely not as daunting as you think, especially if you have a great team/support network behind you. Just enjoy yourself and remember it is all for a good cause, every penny counts and is so appreciated.



## Teens pizza party

Do you like pineapple on your pizza? Our occupational therapist, Sandra, supported a group of teens to create their own pizzas from scratch at our pizza party! Sandra showed the best ways to cut up toppings and there were many laughs and giggles as dough was stretched out and toppings picked.

## Cerebral Palsy Scotland conference and drinks reception

Join us on 3 October 2023 for our 10th annual conference at the DoubleTree by Hilton Hotel Glasgow. There is no cost for delegates to attend. Register here:



A huge thank you to Digby Brown for supporting the conference.

**DIGBY BROWN**  
because it matters...

Following the conference you are invited to attend our drinks reception from 4pm at the same venue. This is an excellent opportunity to network with other delegates, speakers and supporters and meet our new gift in Wills partners Thomas Bradley & Co, who are sponsoring the reception. Come along and find out more about the gifts in Wills service.

**THOMAS BRADLEY & CO**

We are very grateful to everyone who leaves a gift in their Will. Large or small, a gift in your Will helps build a future where every person with cerebral palsy in Scotland has life-long access to knowledgeable, compassionate services and support.

If you would like to discuss how a gift in your Will could support people with cerebral palsy in Scotland contact **Kelly.Kolatowicz@cpscot.org.uk** or on **0141 352 5000**

## Adult summer lunch

Adults with cerebral palsy and their friends, family and Personal Assistants came along to our shared lunch in the centre. We had a lovely afternoon chatting and playing games. It was great to see everyone and we are looking forward to the remainder of our summer events.





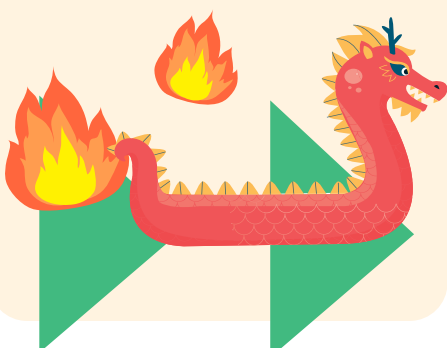
## Allied Vehicles Group

A special thank you to our corporate partner, Allied Vehicles Group, for their incredible support this year.

Allied have been instrumental in powering our work. They have participated in challenge events and fundraising - sponsoring both our Burns Night firewalk and Dragon Boat race day. Their charitable trust provided crucial funding for our Baby buds group and we were grateful to have two representatives from Allied, Gemma Zak-Duport and David Facenna, attend our reception at the House of Lords to discuss improving the lives of people with cerebral palsy.

Read more about how they've helped make a difference this year by visiting our website: [cerebralpalsyScotland.org.uk/our-partnership-with-allied/](https://cerebralpalsyScotland.org.uk/our-partnership-with-allied/)

If you would like to find out more about corporate partnerships, please get in touch with the fundraising team at [GetInvolved@cpscot.org.uk](mailto:GetInvolved@cpscot.org.uk).



## Kiltwalk

We have had a fantastic year for Kiltwalk with walkers taking part in each location across Scotland. Despite the drizzle, Glasgow was a knockout with 47 #TeamCPScot walkers raising a whopping

**£26,476!**



A special thank you to Team Nate and Team Arlo for their fantastic efforts. Kiltwalk is a brilliant and uplifting day out as well as a great way to raise money to power our work for people with cerebral palsy in Scotland.

## Meet Alan

Alan talks about his experience of coming back to Cerebral Palsy Scotland as an adult and the impact therapy has had.

“ I'm Alan and I've got cerebral palsy, I love sport, I love music, I have a passion for DJing, and I love socialising and exploring different cultures as well. I went to Stirling Uni for four years, I used to compete for Scottish Disability Sport in swimming - I was the captain. I still love to compete in sport.

I heard of Cerebral Palsy Scotland initially when I was a young child through my mum. I attended a few times as a young child and it really, really helped me. And then, I moved to where I work now and one of my manager's granddaughters has got cerebral palsy. I recommended that I'd been to you and I didn't know if your services still existed because it's been many years. When I realised that there were adult



services available. I got quite excited and then I attended and it was one of the best things I've done. You have really, really helped me which was just recent so thank you very much for that.

From when I was a child Cerebral Palsy Scotland really helped me and set me up with various skills that I could do that really enhanced my mobility and my general quality of life to be quite honest. And we still implement a lot of the stretches that were suggested to us by the specialists. I had a very good relationship with the team and I have really fond memories of that time.

Continues... 



As I'm getting older, I've found certain things become a bit more challenging. Because you guys are specialists in cerebral palsy, I felt this was the best place to explore and work through this. I know some of the work that we do can be pretty tough but it's been really, really beneficial and that's why I wanted to get back involved.

The challenges I was finding was I just moved into my own flat, and as a result the physio that I used to do with my mum had reduced, and I wanted to be as self-sufficient as possible because I'm quite stubborn in that way. I wanted to have exercises that I could implement myself. So for example putting my socks on was a nightmare and also getting in and out of a back seat of a car was tough. So those were two things that we isolated as two exercises that we could potentially do to improve and I'm happy to say that a twenty-minute struggle after a swim putting my socks on is reduced to five minutes now and that's thanks to you and it's been really, really useful, it's been brilliant.

Another thing was the fact that I was having a lot of pain in my neck and I was struggling with it a little bit. The Cerebral Palsy Scotland

physio was able to give me really quite simple exercises that I could do myself. Now, I can honestly say that I've experienced pain only two or three times since doing the exercises regularly. That was thanks to the occupational therapist and physio at Cerebral Palsy Scotland who worked really well together.

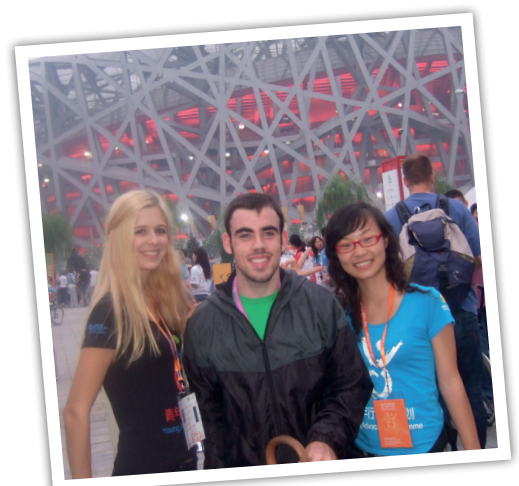
Coming here has made a massive change to me. My whole pain management has totally changed and therefore my energy levels have increased massively. I've also found that getting in and out of cars is a lot easier - people have really noticed it. And just general day-to-day life has actually become far easier for me since going to Cerebral Palsy Scotland.



I would advise anyone with cerebral palsy to get in touch with Cerebral Palsy Scotland because you understand it to a level that I don't think you can find elsewhere. You are so approachable and come at it from so many different angles that it just breaks down

something that you've been worrying about for a while. I was really worried about struggling to live on my own or really struggling with pain and it's just been completely put in perspective and it's just made everything so much easier for me. When I first attended as a kid you were able to advise places that I could go and meet other people with a disability which increased my social circle and made me feel generally more ok with my disability. So across all ages, I would advise people to come. And for family members, I know it helped my mum as well - so yeah, just always get in touch.

I just want to say a massive thank you - what Cerebral Palsy Scotland offers is very unique and it's very much needed. You've really, really helped me as an adult. I can't even explain. It's really made my life so much easier. I hadn't appreciated the adult services were available and I want to make sure that people are aware of these services. There must be many people like me who have just moved into their own place, or their therapy needs have changed, and I just want to be a voice to say, please go here - it's really, really worth it.





## Is it time for a specialist review?

As an adult with cerebral palsy, it's maybe been a while since you talked with a therapist about how your CP is affecting you day-to-day.

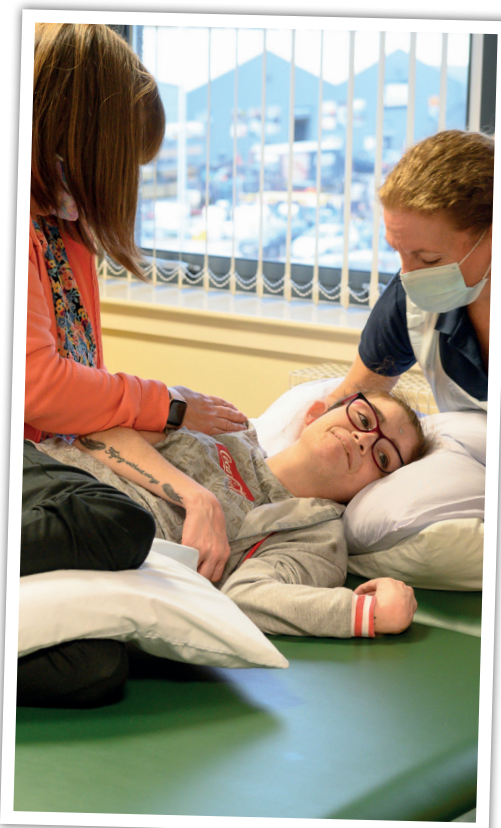
Our cerebral palsy specialist review gives you the opportunity to have an in-depth consultation with one of our therapy team. And we currently have a number of funded specialist reviews available to apply for.

During the two-hour review, you will be able to discuss your cerebral palsy and how it's affecting you day-to-day, ask questions and identify current concerns or goals.

Find out more and apply:



These funded specialist reviews have been made possible thanks to a Scope Connecting Communities Grant from the Charities Aid Foundation (CAF)



**Huge congratulations to four year old Luca Kobelt**, one of the children who attends our centre. Luca won the Dunfermline Press Young community Champion of the Year award for raising awareness of cerebral palsy.

## Words of thanks

We want to say a massive thank you to all our wonderful fundraisers who have raised money to power our work over the last few months. Special thanks to Sean Marner, Gillian Scott, Lisa Harley, David Craig, Nathan Gosling, Iona Fraser, Murray Thomson, Peter Sandwith, Ethan Williams, Michele Aaen, Kieran Haldane, Danielle McKay, Aaron Ormiston, Jennifer Cranston, Gary Lee Cranston, Jo MacMonagle and Team Bailey, Frances Lander, Derek Stewart, Mark Wallace, Jane, Danielle and friends from Stonewood Care Services and the team at Tesco Kilmarnock. **#TeamCPScot**



## Thinking ahead to Christmas

Our fantastic Christmas cards are back. Featuring new exclusive and inclusive designs our selection of Christmas cards supporting Cerebral Palsy Scotland are available to buy in our centre and online. Look out for more information on our social channels.

Every purchase you make will support people with cerebral palsy in Scotland.



## World Cerebral Palsy Day, 6 October

To mark World Cerebral Palsy Day can you help raise awareness of cerebral palsy by asking your local school to do something special? Cerebral Palsy Scotland can help by providing resources to help children learn more about the condition.

Whether it's an assembly, lesson, dress down day or bake sale, we want schools all over Scotland to join us in raising awareness of cerebral palsy.

For more information or to take part please contact [GetInvolved@cpscot.org.uk](mailto:GetInvolved@cpscot.org.uk).



### Become our Friend with a regular gift

As a Friend of Cerebral Palsy Scotland your regular donation will provide vital physical and emotional support so that every person with cerebral palsy in Scotland can reach their full potential.

Scan here for more information:



### You've got to be in it to win it!

Glasgow Community Lottery is a fun way to support Cerebral Palsy Scotland and be in with a 1 in 50 chance each week to win a prize, with a top prize of £25,000!

Tickets for the lottery cost £1 per week and 50% of the funds come to Cerebral Palsy Scotland with the remainder going into the prize pot and supporting other great charities in Glasgow.



18+ only

To take part, visit our website:



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