

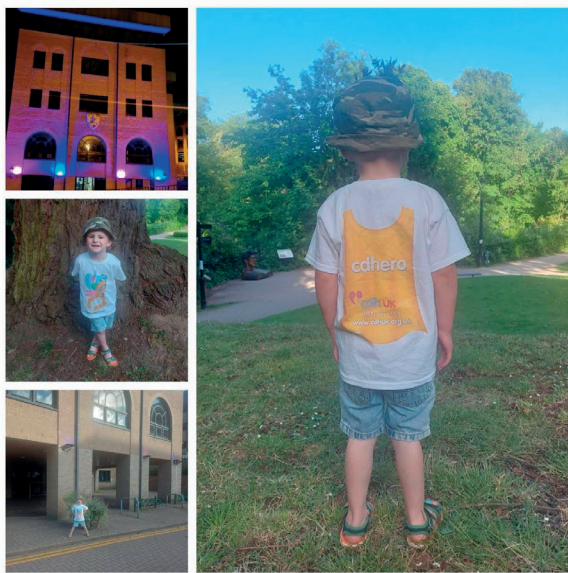
The CDH Magazine

EDITION 4 2024

Hello and welcome to our 2024 edition of the CDH Magazine!

Share some truly inspirational stories from our CDH UK families inside this year's annual magazine.

2024 Awareness



& Colours 4 CDH

2024 Snowflake Appeal



Our CDH Warrior Cayden starting school in September, over come so many hurdles since birth, he really is the bravest Soldier. Forever Thankful xx

Nanna xx

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10 Dec 2024

Your donations to the snowflake appeal help us to continue supporting families affected by a CDH diagnosis and outcome.

Our Fantastic Fundraising CDHeroes!



cdh UK

The Congenital Diaphragmatic Hernia Charity



Chairperson's welcome

This year I am writing my welcome with a certain amount of trepidation as to how I am going to get organised for the festive period in time this year. It is mid December and I still haven't bought a single present or sorted out my food list yet. My tree is only just decorated and don't even talk about the forgotten hair dresser appointment! I then remember that this is totally normal and how most people feel as the beginning of December creeps up on us and passes quickly by.

Feeling pressure at this time of year is all too familiar and even more so when you have young family and a child with additional needs, a child in hospital, facing a CDH diagnosis or in the depths of bereavement. The thought of being around hordes of shoppers, eating out or visiting friends and family can quickly become a huge anxiety and so my thoughts quickly turn to all of you reading this that are more than likely feeling much more under pressure than I am. So with this thought, I extend an encouraging 'we are always here' message. Our team at CDH UK are here to support you through what can be a really difficult period for some. You can get in touch through our website www.cdhuk.org.uk where you will find contact details and lots of information.

We hope to bring you more new resources during 2025 and we hope that you will Join in June 4 CDH to help raise awareness and funds for our cause.

Thank you for supporting CDH UK again this year and a special thanks to our wonderful team at CDH UK for another year of commitment to our community.

On behalf of them all and myself we wish you all a Merry Christmas and a Happy New Year.

Bev x



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Impact Statement



2024

Impact review



The Congenital Diaphragmatic Hernia Charity



Making a difference



Our Vision Our Mission: Through information, awareness and research, CDH UK is supporting patients, families and healthcare professionals and helping to improve outcomes for those affected by Congenital Diaphragmatic Hernia & Eventration of the diaphragm.

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VOLUNTEERS

From Management Committee members to support pack co-ordinators, supportline handlers to fundraising administrators, Family Liaison Volunteers to Bereavement Buddies, Awareness Merchandise admins to Trustees and more! They gave their spare time, skills and love to help our cause!

over 10



Research Publications

We have authored and co-authored over ten research papers to date. These help improve outcomes for patient and their families and to educate healthcare professionals

OVER

£850,000

DONATED TO RESEARCH

We grew our Research fund even more during 2024 to add to our already amazing total above! We hope to grow this further in 2025 and contribute even more!



MORE THAN

£40,000



granted to supporting patients and families. This helped with the additional costs of having a baby/child in hospital or with additional needs. It included helping families to have a much deserved break away and help with accommodation for fetal therapy.

4000



HOURS

Is the minimum hours worked by our volunteers to provide services and resources to support families and research

1000'S



SUPPORT PACKS, INFORMATION BOOKLETS & MEMORY BOXES

Distributed to families comprising of newly diagnosed parents, bereaved parents, School starters, Healthcare providers

What will you do to support us?

How will you help to improve outcomes?



Volunteer



Partners



Fundraise

DONATE NOW

FREEPHONE SUPPORTLINE

0800 731 6991

email support@cdhuk.org.uk

SOURCES

<http://www.cdhuk.org.uk>

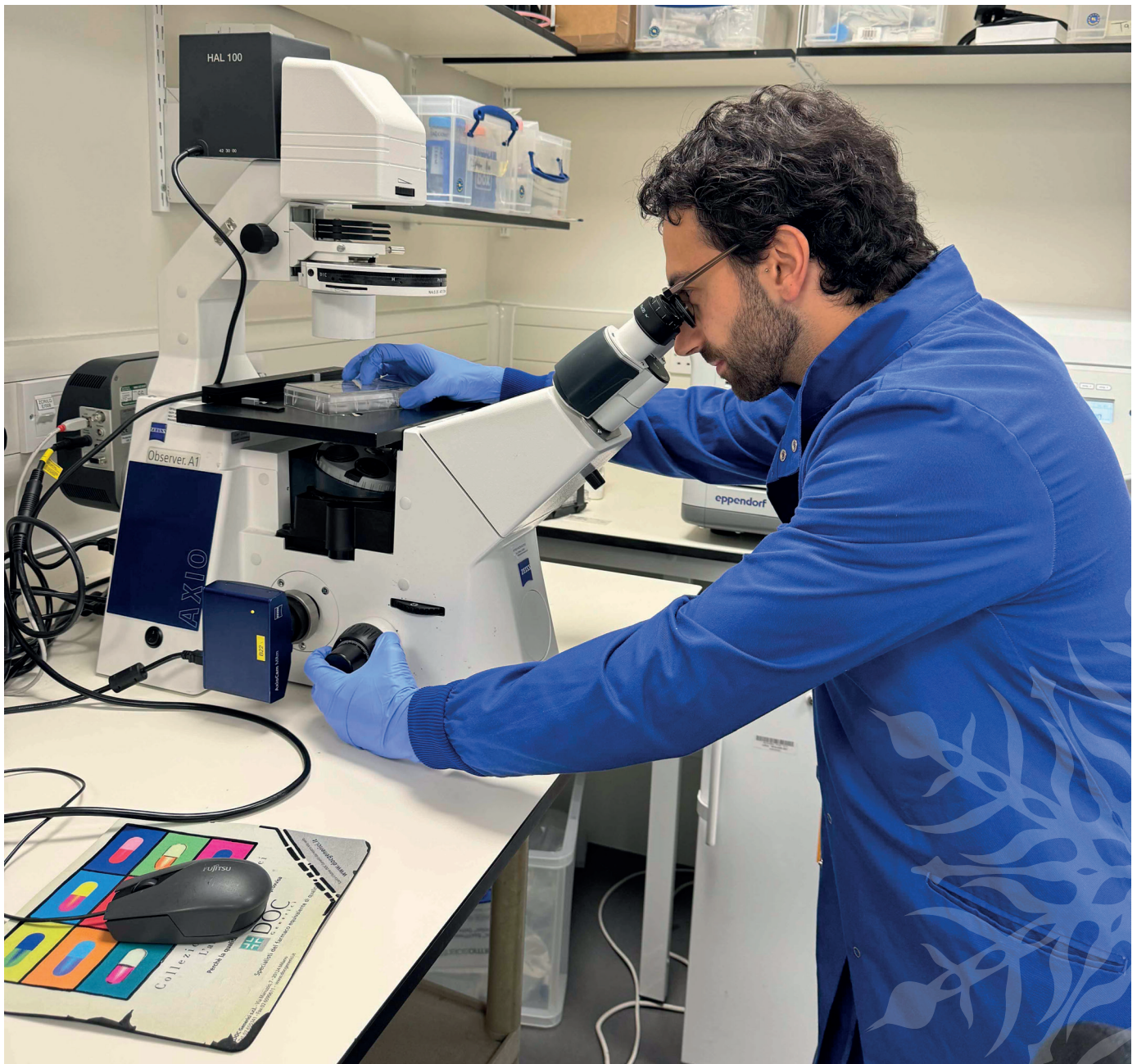
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CDH UK - The congenital Diaphragmatic Hernia Charity



CDH Research HUB

We continued to contribute and fund research during 2024 and were pleased to award funds to three new projects last year that we have seen commence in 2024.



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CDH Research HUB

We also visited the Zayed centre for Rare Diseases in London this year to see first hand the exciting work being carried out, that could mean a new tool in CDH severity prediction in the future.

We met with some young scientists and were shown around the amazing facilities. We hope to support this research and work with the team at next year's CDH Community Conference at the Institute of Child Health.



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Collaboration **Ernica**

This year the annual ERNICA meeting took place in Wroclaw, Poland. Unfortunately CDH UK were unable to attend in person this year but we pre-recorded a presentation on patient priorities in research, which we feel is an important area of consideration for researchers.

The meeting went well and one of the main topics was quality of life. Further guidelines were worked on for other conditions and work continued on patient registries.

The photo shown is of other patient representatives for other conditions who are all working hard like CDH UK to make a difference.



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CDH Stories

All the following CDH stories have been sent in by a family member and are supplied in their own words. The only amendments made by the editor are for incorrect spellings.

Oscar's Story

Hey there,
This is my son's story.

Oscar was my first child & I was so excited! I went to my first scan and everything was fine (I was so happy to see my little baby on the screen).

We got to our 20 week scan and I knew straight away when I saw the lady scanning me, she was looking really closely at my scan, she said to go out for a walk and to come back, so I did and there were 2 people waiting to scan me again. I got in the room and they told me that my little boy had left CDH - I didn't know what it meant or anything, they then gave me a leaflet and quickly transferred me to Sheffield.

I was then quickly seen at Sheffield. They sat me down to explain everything and they said that my baby boy had only a 50/50 chance of survival. I was devastated.

We then went on to having scans every 2 weeks and he was staying stable and fighting. It got to the week before my due date and they decided that the best option would be to have a natural birth, but when we got to the day nothing was progressing so we had a c section.

I was terrified, paediatric doctors were there waiting for my little boy to be born.

He came out screaming at the top of his lungs! I didn't get to see him. They rushed him straight away to get him on the respirator.

I didn't speak or anything. I just laid there and froze, just praying that Oscar was going to be ok.

When I came out of recovery, Oscar's dad went straight to see him. He came back to me so upset. I thought something was wrong, but he was just so upset to see Oscar connected to all these wires and machines.

Finally, when I was able to get out of bed and into the wheelchair, I could go and see Oscar.

I knew straight away he was a fighter!

He opened his big blue eyes and gripped my finger so tightly.

2 days went by and he was ready for his operation to repair the hole in his diaphragm. The operation took around 4 hours and he came out of it looking better than ever!

After a few weeks Oscar finally came home, with no tubes, wires or anything!

He'd done so well!

Oscar is now 8 years old and goes for regular check-ups every 6 months!

I always remember his doctor saying he'll never be a footballer because he only has half of his left lung.

But that is his favourite thing to do and he loves it!

It was the scariest time of my life, but I'm so happy now and extremely proud of Oscar!

Oscar's mum, Rebecca.



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Abigail's CDH story



Hi there,

I found your charity doing some general googling and thought that I would share my story.

I was diagnosed with CDH at birth by a nurse who noticed my breathing.

My condition had gone undiagnosed in prenatal scans.

I had surgery 2 days after birth and it was successful.

They recorded my breathing to use for trainee nurses/ doctors, as it was a classic case of CDH breathing which is interesting.

My scar got infected so it's probably a little more visible than the usual.

I suffer no prolonged issues that I'm aware of after 17 years, apart from tightness around the scar area, but it doesn't really affect my everyday life. Of course, my scar is visible - probably a bit more than the average CDH because of the infection, but I've never been bothered by it. People have asked me and I've simply told them my story, or told them I was bitten by a shark 🦈.

People do have a double take in social situations, but I've never been bullied, or had nasty comments made, it's a part of what makes me, me - therefore it is never anything to hide!

I do have my concerns, what will happen when I have kids in the future, will they have the same thing? But there is so much support and information out there and being a survivor myself it's not a forefront problem.

I'm active and enjoy fitness and the gym. The condition has not held me back in that sense. I do think it has caused me to have a fast metabolism, but again not something that has massively effected my life.

I plan on going to university next year and I am becoming an adult soon which must be amazing for my parents to see after having a 50/50 survival rate after I was born.

Just thought I would share my story.

I now have a CDH Christmas ornament on my tree 🎄.

Hope whoever reads this has a good day.

Abigail



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Bartley's CDH story



So, when my son was born at 37 weeks, he was born healthy. A little small at 4lb 10z.

After 8 days of being in the RVI, as that's where he was born, we were allowed to come home.

All was going well with Bartley up until he was 6 weeks old.

The day started as just a normal morning. I gave Bartley his milk, settled on the sofa beside me and I noticed he started gasping for air so I immediately rang an ambulance and they came and they had him on oxygen right away. His skin was extremely mottled & cold.

We got to A&E and they took him to resus. At this point he was surrounded by lots of doctors, nurses & specialists. They had no idea what was wrong with him. They started using heat mats to try & get his little body to warm up but it wasn't working. They couldn't get his veins to rise to give him medication, so they had to inject directly into his bones.

Bartley was on oxygen for quite some time and after a long couple of weeks he slowly started to get better, so they decided to treat him for bronchiolitis.

So again at 8 weeks old, the same thing happened again. We went back to hospital. They did more tests, more oxygen, more needles, more worry and stress. Everything was feeling out of control and it was so difficult to handle, because all I wanted was to make him better and happy again.

Bartley had another episode while still in hospital, so then they decided to give him a full body scan, where they then found that he had a hernia in his diaphragm. Bartley was then taken into intensive care, ventilated and intubated.

The decision was made to transfer him back to the GNCH (Great North Children's Hospital) in Newcastle so that he had the best chance of survival, as the hospital we were in, in Cumbria didn't have the facilities for what Bartley needed. Bartley started to be ventilated and intubated for a while, to let his body rest.

A couple of days after Bartley got to the GNCH he went to surgery for them to try and repair his CDH, which luckily, they did and they repaired it naturally without any patches being needed to hold the hole together. It was touch and go for a long while whether Bartley would make a full recovery, as his little body was so close to shutting down.

After numerous hospital trips, tears, worries and every emotion possible.

Bartley is now 3 years old and he's such a strong little boy.

He fought so hard to stay with us and I'm forever grateful to everyone who looked after him and made his recovery possible.

I'm so proud of Bartley for being the little inspiration that he is.

He'll always be mammy's little champion.

Thank you so much for reading my story.

Kirsty Featherstone.

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Amelia's CDH story

Hello, my name is Georgia.
I am Amelia's mum.

Here is Amelia's story!



Amelia was diagnosed with CDH when I was 14 weeks pregnant.

Every 4 weeks I was having appointments with the Fetal Medicine Unit. Completely unaware of all of the other conditions that can occur with having CDH.

Amelia was born and intubated straight away at birth. I was told that she had severe pulmonary hypertension, all within half an hour of being out of theatre, as I had an emergency C Section.

The doctors, consultants and nurses were really struggling to stabilise her SATS.

I was told a couple of times to prepare for the worst as they were really struggling.

At day 6 of life, the doctors mentioned that with them struggling they thought ECMO would be the last resort to help her. We got blue lighted to Great Ormond Street Hospital, where the next day I got the call to say they had to put her on ECMO as an emergency, as her SATS had dropped and wouldn't go back up.

At 3 weeks of age Amelia had her CDH surgery.

At this point I felt I was so used to signing my life away! Not knowing the outcome as she was still critical. The surgery went well and she came back with a chest drain in!

Amelia had a mass on the left side of the lung which tested positive for lymphangiectasis. This meant she still had the chest drain, plus another on the other side, for couple months!

When these drains came out Amelia was doing very well, but was still not being able to tolerate feeds! Amelia had lots of scans and we found out she had malrotation.

She still couldn't tolerate feeds, they then opted to have a PEG-J inserted.

Since this procedure Amelia tolerates her feeds!

Amelia has bad reflux and is on a few medications for the issue, but as she's growing it is seemingly getting better, but she just has her good and bad days with it.

We spent 7 months overall in hospital, which was very long and took a major toll on my mental health, but I now have my girl home and would do it all again for her!

I now have a happy 8 month old child!



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Alfie's CDH story



"We've got to keep going, we've got to keep pushing on"

A story of a mothers' love...

When I was a young girl, I never really thought about having children. It was always something in the back of my mind, but I guess I always took it for granted that it would just happen at some point and never really thought it through. But then I met Matt. The man that my Mum had always told me about...the one who stole my heart from our first date and the one I just knew I would marry.

Matt and I met in our thirties and we both knew we wanted to start a family. We agreed that we just wanted one little one and a dog and then our family would be complete. So, we decided that we would try and see where our next adventure took us. But then the Pandemic of 2020 arrived and we made a decision that with the unknown in sight it would be best to put off having a baby until it had passed. Both our families lived far away and we couldn't imagine not having them around to support us.

But fate made a different decision for us and within 4 weeks of being locked up in our little cottage, zooming friends and family we found out we were expecting, and we couldn't have been more thrilled. We were finally going to have a little person living with us and we just couldn't wait!

Neither Matt or I never had any patience back then and come 16 weeks we decided to have a gender reveal scan so we could get organised and start buying lots of baby bits. Convinced we were having a little girl we were completely shocked when the sonographer announced we were quite clearly having a boy who also had a lot of personality judging by the sans we all saw! 'A boy!' the words kept swirling around our heads... what would we call him?



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Alfie's CDH story (continued)

Then amicably over dinner one night we both fell in love with the name Alfie. "We will call him Alfie Simon Perkins!" we both agreed and the excitement we both felt was indescribable.

Time passed and soon we were at our 20-week appointment. It was quite daunting entering hospital during the pandemic. Everyone would wear masks and you would have to wait in your car until the nurses were ready to see you. But on this occasion Matt was allowed to come with me to see our boy.

But within minutes of scanning my bump the sonographer explained there was a problem with the scanning machine and we had to switch rooms. At the time we thought nothing of it but not long after we were taken in to the family room and our realisation to what we would have to face soon became apparent.

Alfie's scan showed that his lungs weren't forming properly and his main organs on the right side of his little body were developing in his chest cavity. We were completely devastated and in shock. Why us? Why was this happening when we had longed for this baby for so long? Bad luck they said but that didn't help to mend our broken hearts.

The foetal medicine midwife explained that we would have to go to Liverpool Women's hospital for a second opinion and along with chromosome tests we agreed to go and have the exact condition confirmed so we knew what would happen next.

Our appointment arrived at Liverpool Women's Hospital and everybody was so lovely to us.

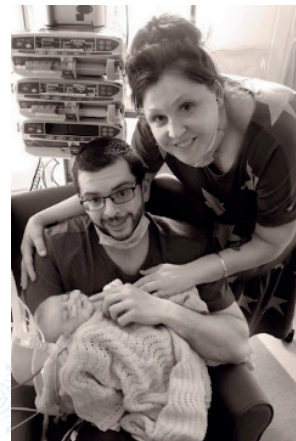
After the scan we were taken to a family room where it was confirmed that Alfie had Right Sided CDH. We were devastated but with a 50/50 chance of survival we knew our boy deserved that chance.

Moving forwards with the pregnancy both Matt and I researched into foods that were good for lung development and I lived off a diet of broccoli soup, apples and adding extra garlic to my meals. I felt good and Alfie was growing well. We knew we were growing a strong boy and had every faith that our boy was already a warrior before even meeting him.

Due on 16th January 2021, Liverpool Women's decided to induce me on the 10th with everything in place for when I gave birth to our boy. This would have been all going to plan but Alfie had other ideas...

On 8th January at 9.15am we welcomed our beautiful Alfie to the world, weighing 7bs 4oz. He was the most beautiful little boy and after all the commotion of him arriving we were finally allowed to hold him once he had his breathing tube. These beautiful big eyes were looking back at me and whilst trying to come to terms that we were now parents I couldn't help but feel completely overwhelmed with love for this boy. How did we create something so beautiful?! As the nurse took him away to the ICU department, I muttered to him "be a good boy!" a silly statement in the grand scheme of things but Alfie knew what Mummy meant.

Time passed and we were finally allowed to see Alfie in the afternoon. He looked so small attached to all the wires and breathing machine. It was heart breaking to see and we cried and held his hand for hours. None of us knew what the future would hold and it was such a mix of joy and heartbreak all at one time. We took so many photos of us together not knowing if this would be the last time no matter how morbid that sounds.



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Alfie's CDH story (continued)



Alfie's first 24 hours were eventful and by the next day he was put on to the oscillator to help him breathe better. The nurse said he thought he would have to go on Ecmo so had arranged for Alfie to be transported to Alder Hey Hospital that afternoon.

We arrived at Alder Hey to a whirlwind of commotion around Alfie's bed. They were going to keep a close eye on him over night and monitor whether he needed to go on to Ecmo or not. The next day arrived and with fear being felt with every ounce of our bodies we went to see Alfie to find they hadn't needed to put him on to Ecmo – he had turned it around himself. Over the next few days, the nurses and Doctors were able to reduce his ventilation which were all positive signs.

At 6 days old Alfie was well enough to have his hernia fixed and both Matt and I emotionally waved our baby off as he was taken down to surgery.

It was the longest day of our lives! Alfie was in surgery for over 7 hours and upon returning to the ICU department it had emerged that Alfie had had his whole liver in his chest cavity and the hernia was bigger than expected. The next few days were critical, but our boy was so strong and was fighting hard to survive. However, after a few days it was apparent that Alfie needed extra support and was put on to Ecmo. Something as parents we had tried to avoid but we knew Alfie needed this chance to rest and try and build his strength up.

2 weeks passed while on Ecmo. The nurses had reduced his sedation and for the first time we were able to see his beautiful eyes clearly staring back at us. I started to sing to Alfie and made up a little rhyme of "we've got to keep going, we've got to keep pushing on" in the hope it would give him the strength he needed to carry on.

Once off Ecmo, the consultants sat us down and explained that Alfie was still struggling and the next few hours were critical. We were told for the first

time that there was a big chance we could lose our little boy and our hearts sank. The fear that went through our bodies was soul destroying and we didn't sleep at all that night. By this stage we had kindly been put up at The Ronald McDonald house and we spent the night watching the phone waiting for it to ring. But it didn't...

Over the next couple of weeks Alfie again had turned it around. They started to reduce his sedations and ventilator settings and in true Alfie style was proving everybody wrong. **What a warrior!**

But then the side effects of the Ecmo became apparent. Alfie suffered seizures, had a blood clot on his brain and as if this wasn't bad enough, then developed an aneurism on his neck where the cannulas had been placed whilst on Ecmo. Again, our boy was whisked off for life saving surgery and again we were told it was a 50/50 chance he would survive the operation.

The aneurism was something the consultants had never seen before and were in 2 minds whether to operate or not. We were given the choice and we decided to allow the operation to go ahead...even though we knew that there was a chance we might not have a child at the end of it.

The next 6 hours were a blur. There are no words to describe how we were feeling and the anxiousness going through our bodies. We held and checked our phones every 2 seconds with sweaty palms just waiting for a call that he was going to be ok. Then just like that we were called to be told Alfie was back on the ward and the operation had been a success. For this to happen, they had to block one of the main arteries on his right side that went from his heart to his brain.

The next few days were a test to see if this had caused any paralyse or brain damage – again we didn't sleep for the next few days as we constantly worried if we'd made the right decision and praying our boy would continue the fight to prove everybody wrong.

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Alfie's CDH story (continued)



I remember walking to the ICU unit after grabbing a coffee the next day and one of the Mums stopped me on the stairs to ask how Alfie was. I stood there and for the first time broke down in tears asking her as a mother if I had made the right decision. She offered me just the words I needed to hear and told me that Alfie was a fighter, and any mother would have made the same decision. Because throughout all of this, I never spoke to my own Mum. She was always there for us all, messaging every day. But I couldn't bear to hear her voice. We were miles away from home and I knew hearing my Mums voice, or even speaking about how poorly my baby was would just send me over the edge. I only ever spoke to Matt, the Nurses and Doctors and a dear friend who was too fighting her own battles in the hospital with her daughter. I didn't have time to expose my emotions and fear as I had to be strong for my boy and give him the strength, he needed to survive this.

We continued to stay by Alfie's bed daily, with only taking short breaks for a quick coffee. Every day seemed to fly by and before we knew it weeks had passed, and Alfie was getting stronger. He had started waving his hands around and kicking his legs - mainly when he needed his nappy changing. He was a very calm baby despite everything he was going through. He only ever got miserable when his nappy needed changing or he was over tired - just like a normal baby. We soon got to grips with how he was communicating with both Matt and I and to help the nurses to understand I wrote a 'manual' and included pictures of Alfie so if we were ever away from his side, they knew how to calm him down and it gave us as parents comfort knowing he was always being comforted in the way we would.

Over the next few weeks, his medication was reduced and finally taken off. He started on with about 10 different iv's and it was such a relief as we saw the nurses remove them from the stand that was a permanent fixture next to Alfie. He was moved from

a cot on to a 'Big Boy' bed and this gave him the option to have his name put at the end of it. We were told we could start putting him in baby grows and Matt and I thrived off heading out to the local Sainsburys buying lots of different outfits for our boy. This was something I had never done whilst pregnant as I never felt I wanted too knowing just how poorly Alfie would be.

When Easter arrived, we bought a 'Happy Easter' baby grow and my Mum had knitted some chick booties for him to wear and come the arrival of the Easter bunny, Alfie was the talk of ICU! He looked so beautiful in yellow and took it all in his stride as all the nurses came to complement him on his Easter look.



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Alfie's CDH story (continued)



We saw Alfie smiling, we bought a variety of different books to read to him which he loved and bought some black and white toys which we hung above his bed. He loved these toys and would be fixated on them as they moved in the air – the zebra and penguin being his absolute favourite. He even started to reach out for these at points and we thrived off our boy learning and developing despite still being on his ventilator.

Alfie was getting so much stronger, we were allowed to get him out of his bed for cuddles and as we cradled him, he would fall straight asleep in his Mummy and Daddy's arms – he felt safe with us both. It was like holding a normal baby despite the ventilator and all the wires – this is what it was all about – to have our beautiful baby in our arms.



Things were going well...everybody thought so, and we were gearing up to sometime in the future of bringing our boy home. We planned what we would buy and actually began looking at nursery furniture and how we would decorate our warrior's bedroom – he was going to have the best because nobody deserved it more than him!

Then one morning we came in to see Alfie as we always did, and he wasn't his usual happy self. He looked distressed and had been like it throughout the night. The only way they could keep him calm was to increase his medicines. Surely this wasn't normal? It was a step backwards we thought. But we were assured it was the fairest way to keep him calm and just like that it seemed the past few weeks had been a dream and in the pit of my stomach I suddenly felt we were entering our darkest nightmare. His ventilator settings had significantly increased, and everything seemed to be heading back to where we had just come from. "Alfie has an infection" we were told so a course of antibiotics was prescribed. He had had these before and it had made significant positive change so we waited in hope the same would happen again. It didn't. The next and final step was to try steroids to hope for an improvement. Alfie was given these for 3 days and we were told that if they were working, we would see an almost immediate improvement. So, the next 3 days we waited with the fear running through our veins and we jumped on any positive change to prove that Alfie was getting better again. And rightly so, the consultant agreed positive changes had happened so we extended the course for another 2 days in the hope things would just keep on getting better. 2 days passed and we continued to hold Alfie's hand, read, and sing to him so he knew we were still there by his side. He was heavily sedated at this point, but we had to let him know we were there with him – the three of us were in this together.

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Alfie's CDH story (continued)



Then late that afternoon we were called for a meeting with ICU staff to discuss Alfie's progress and how he was doing. Everybody was very upbeat and a part of me thought that the steroids had worked and things were going to get back on track.

"The steroids are not working and sadly there is nothing more we can do for your Alfie" this sentence still rings around my head every day. What did they mean there was nothing more they could do?

He was in one of the best children's hospitals in the world...how could he not be getting any better? Matt grabbed my hand the tightest he ever had as the silent tears ran down my face. I was numb and couldn't believe this was happening. I was so cross and upset and in disbelief. This was the moment I had been avoiding for my son and my family but here it was as clear as daylight. What were we going to do?

I left the meeting and just went straight to Alfie and held his hand. There was a lot of commotion in his bay but all I could think was I was going to lose my beautiful boy and how would life go on without him.

The Matron on duty made sure he had his favourite nurse that night and I am forever grateful for him having her – she was one of the ones who treated Alfie as her own.

We left the hospital and headed back to our room at Ronald McDonald and neither of us could believe this was happening. We barely slept that night and were straight back by Alfie's side the next morning. I spent the morning reading him Peppa Pig books and holding his hand, but I never let him hear me cry. He didn't need to hear the pain I was feeling as he had fought so hard to be here and I needed him to know just how proud of him we both were.



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Alfie's CDH story (continued)

Alfie passed away later that day after one of the most heroic fights a 5-month-old baby has probably ever had to endure. We cradled him in our arms for hours and in a perverse kind of a way, it was a comfort knowing he was no longer in pain and that we could finally cradle our child without the wires and breathing tube.

I remember singing 'Twinkle Twinkle little star' to him as I looked out of the window – there was a dark cloud to one side and sunshine to the other... but no rainbow. It was the visuals that summed up our fight the past 5 months. Now we always say that Alfie brings out the sunshine on the darkest of days.

We moved home back to our family in the Cotswolds and laid Alfie to rest down the road from us. He lies in the most beautiful grounds and is very close to his Great Grandma and Grandad, so we feel a sense of him being in good company. Matt and I got married 5 months later on 26th October to solidify our love for each other – I would not be where I am today without my wonderful husband and nor would I have the strength to write this story.

In addition, the support and love we have had from our family and friends have been beyond incredible and as we try to rebuild our lives - we are forever thankful for that love.

We still hold the upmost love for our brave little boy and forever live our days for him.

**If love could have saved, you Alfie...
you would have lived forever.**



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The International CDH Symposium

The International CDH symposium is held every two years to showcase research and run workshops for Clinicians and other allied healthcare professionals and to also bring together patient organisations and healthcare professionals under one roof. It is organised by the CDH Study Group and the CDH Euroconsortium. The 2024 Symposium was held in the beautiful French city of Lille.



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Two representatives from CDH UK attended the event and the CDH Patient Journey (by CDH UK) short film, that was produced to complement the CDH Patient Perspective Journey publication, was launched during the event.

Patient representatives were also invited to be part of a panel for one of the plenary presentation sessions centred around family support. This was welcomed by CDH UK as an essential element to the Symposium.

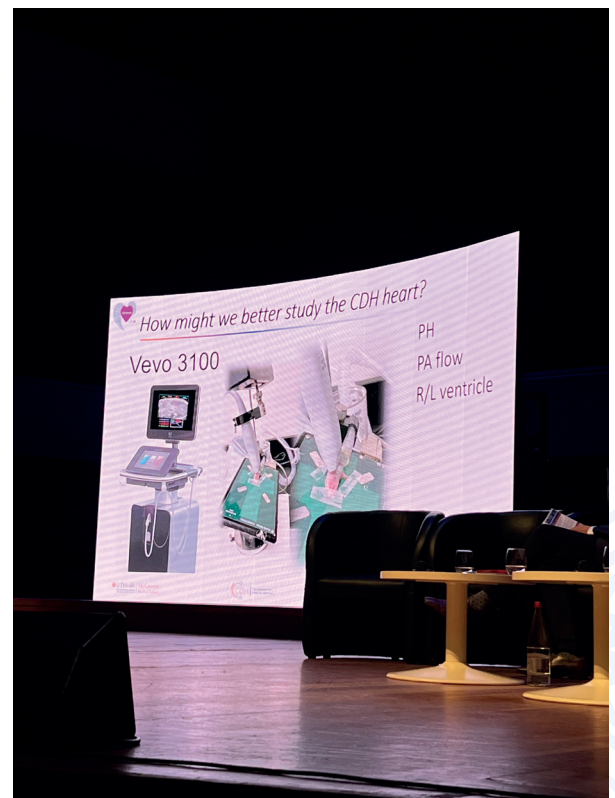
The three day event was extremely well attended and we were very proud to see all of the research supported by CDH UK presented during plenary and poster sessions and to receive such positive feedback on our work to date.

It was a very interesting Symposium focusing on the various elements of CDH such as the diaphragm, heart, lungs and we were extremely grateful to see the amazing work going on particularly around follow up, mental health outcomes and family support.

Roll on CDH 2026!

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Our Fundraising CDHeroes!

This year we have seen lots of CDHeroes raising awareness and funds for our cause. As a charity with no government support or regular sources of income from grants, we rely solely on volunteer donations. So thank you from the bottom of our hearts For supporting CDH UK during 2024, whether that be through fundraising events, donations or the purchase of our merchandise.

Here are a few of our CDHeroes at work to inspire you!



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Our Fundraising CDHeroes!



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Our Fundraising CDHeroes!



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Support feature

The festive period normally involves social events and gathering of family and friends. These events often involve food and lots of it. Eating greater amounts than we are normally used to and sometimes of richer types containing more fats, spices, salt and sugars, can often lead to children (and adults) suffering from digestive issues and those with CDH can experience more discomfort than usual.

In addition to tummy troubles, children with CDH can often experience feeding challenges and eating new foods in new environments can be even more challenging for them, their parents and carers. Textures and new tastes can be problematic and overpowering flavours can be too much for sensitive taste buds. Sometimes children need tube feeds, extra meals or supplemental oxygen and this can mean having to transport extra items and equipment. This can cause additional stress especially if travelling by public transport.

Parents and carers can also be anxious about the thought of their child being surrounded by lots of people from different households in a season where viruses are doing their rounds. So buffets and lots of close physical contact can add additional anxiety for many a parent or carer. There are often lots of children around too and this can lead to rough and tumble play that parents and carers can worry about, especially following surgery or with tubes involved. For some children with autism or other neuro-diversities a social event can be very overwhelming or overstimulating.



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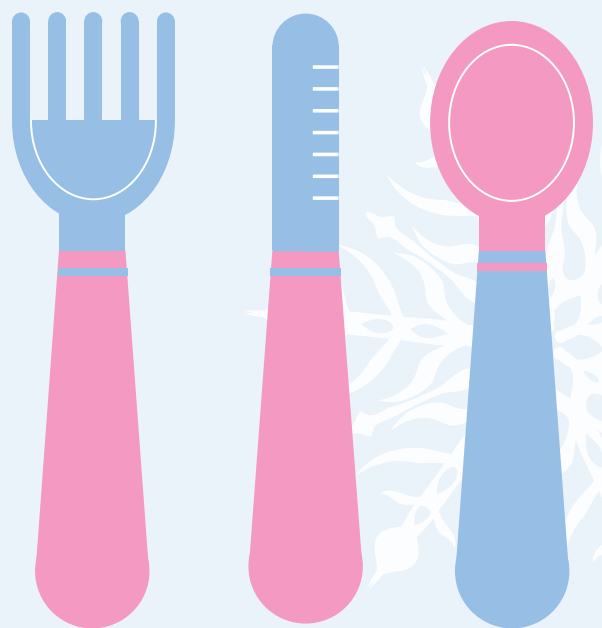
Support feature

All of this added stress during the festive season can be really difficult for some. So we have put together some tips and advice below to help you plan ahead and help you through so that you can relax and enjoy these social events like everyone else!

- Make a list of items you need to take with you in advance
- Ensure you have ordered repeat prescriptions before pharmacies close for the festive period and that you have supplies of everything you need
- Check vaccinations are up to date
- Find which emergency GP surgeries and pharmacies are open over the festive period
- Take eating utensils and food containers that your child is used to eating with along with you
- Make the host of the event aware of any allergies or special dietary needs well in advance
- Make up food in containers that your child will normally eat so that you have a back up in case they won't eat the food where you are going, or in case they have any allergies or intolerances that haven't been catered for
- Teach good hygiene and handwashing practices
- Cancel if you are aware of any guests that are ill or if your child is ill or has had any contagious symptoms within 48 hours of the event
- Explain to the hosts beforehand if there is anything you are worried about so that they can prepare and reassure you in advance
- Request access to a quiet place to calm a child who is likely to have a meltdown, to tube feed or administer medications
- Ask guests not to hug or kiss your child to reduce the risk of spreading germs or overwhelm them
- Practice some breathing techniques for if stressful situations arise
- Finally you can always decline an invitation!



Remember that things are rarely as bad as we anticipate and people are usually very accommodating and understanding of people's worries and needs. Anxieties quickly disperse once we feel more in control of situations by adopting some preplanning. If you feel overwhelmed or over stressed please do not hesitate to contact our team by emailing support@cdhuk.org.uk or using our supportline **0800 731 6991**



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CDH Community Conference

We were very excited to have been invited to Belfast to host our CDH Community Conference (CCC) in partnership with the Queens University Hospital Belfast.

The conference took place at the amazing W5 event space in the heart of the city, offering attendees the opportunity to explore the interactive exhibits featuring nature, science, media, and much more!



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CDH Community Conference

Attendees were a mixture of families and healthcare professionals who were invited to listen to presentations from CDH UK, Surgeons and other healthcare professionals. Afterwards break out group sessions were conducted to find out patient priorities and to understand their experience with CDH better. The children were entertained with arts and crafts and of course the delights of W5 and all enjoyed a buffet that included an amazing CDH UK cake!

Families mingled and got to know each other and we hope that lifelong friendships were formed.



Special thanks go out to Dr Patrice Eastwood from Queens University, Belfast for her invitation and help with the event.

Our next CCC will be held on Saturday 21st June 2025 at The Institute of Child Health, London with full details being released early in the New Year. We look forward to seeing you there!

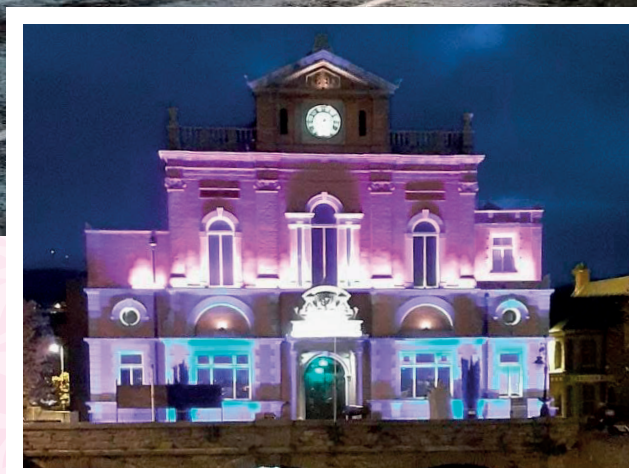
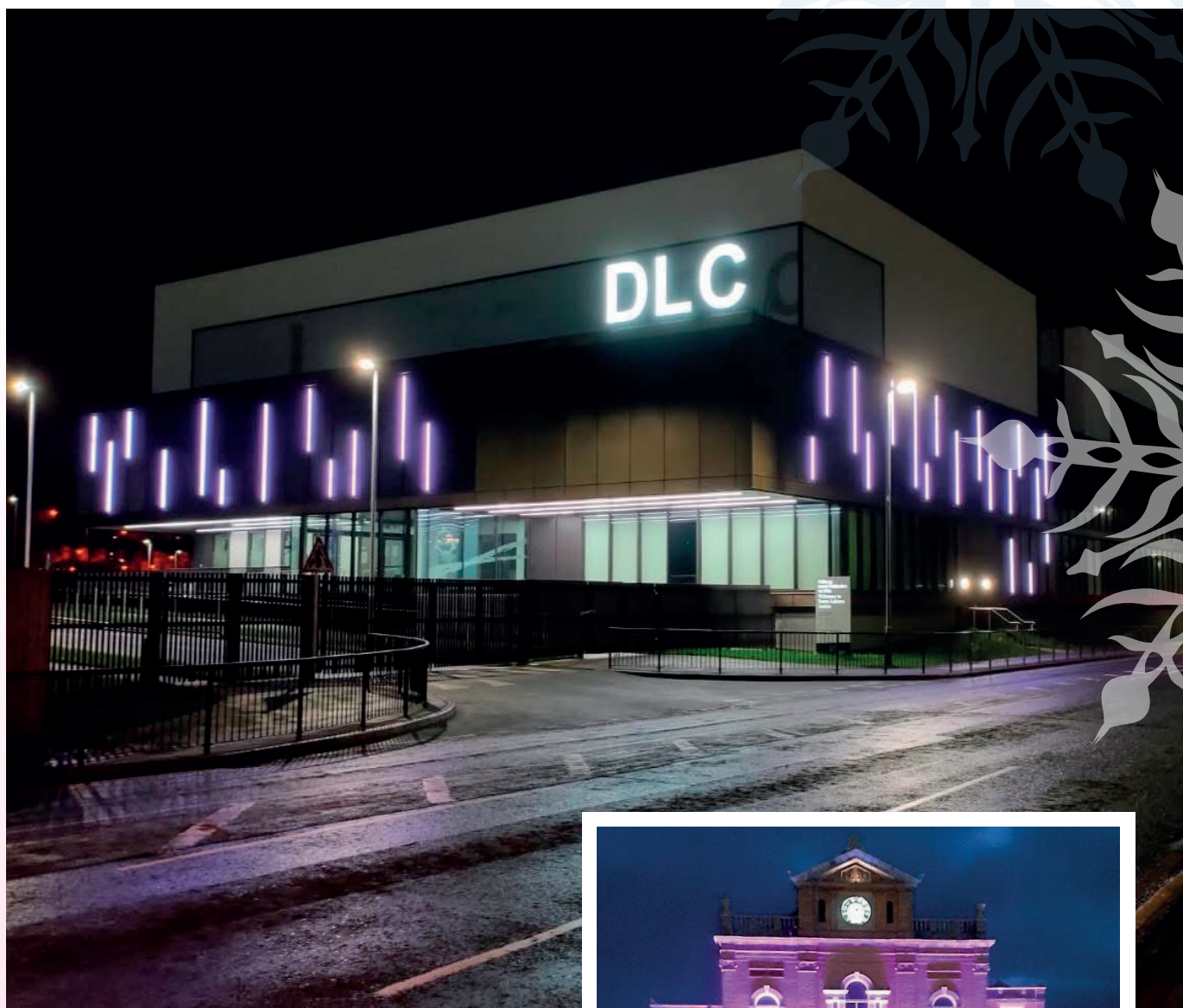
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Awareness 2024



'Join in June' 2024 involved a great first time fundraiser for us which was Bounce 4 CDH, which involved participants completing an inflatable obstacle course to raise funds and awareness for CDH UK!



Colours 4 CDH

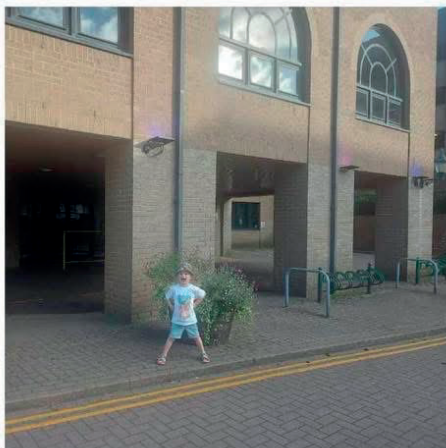
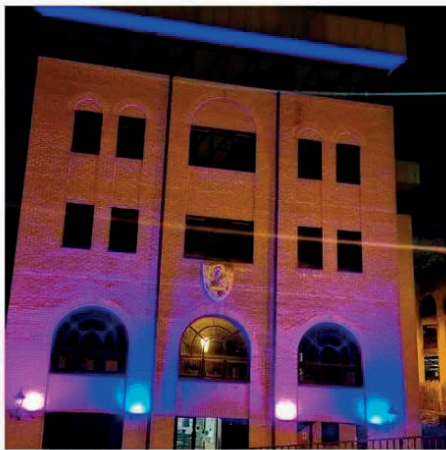
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Awareness 2024



This was open to children and adults and was enjoyed by all. Thank you to all participants for supporting our cause and hope you will join in next year.



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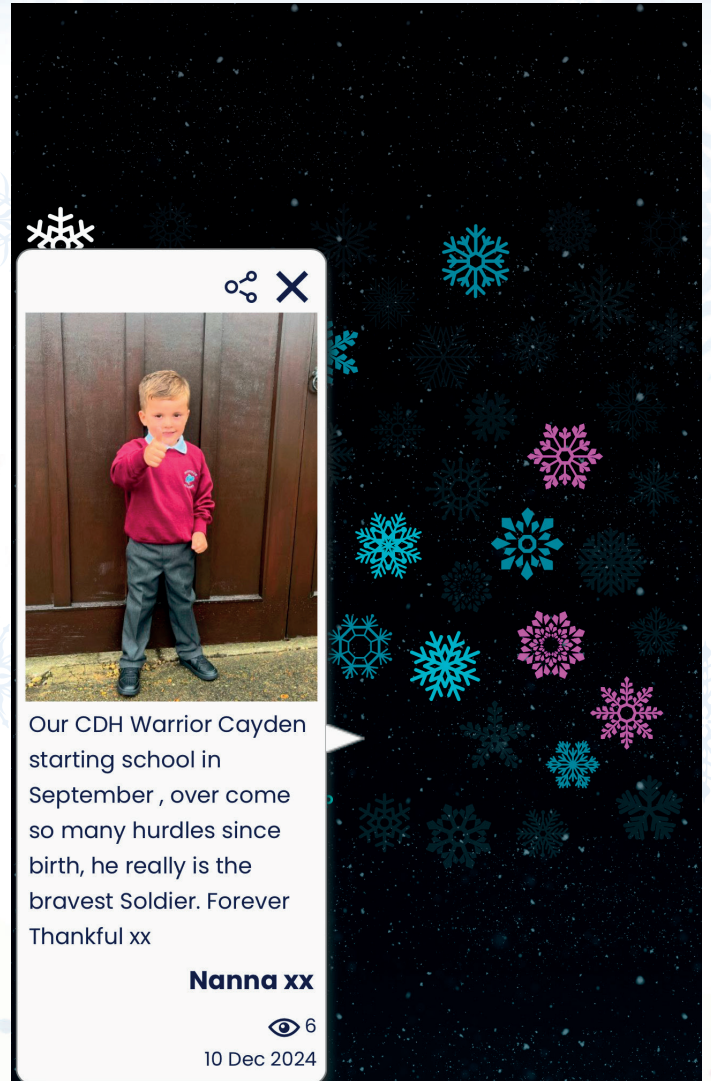
2024 Snowflake Appeal

Our 2024 snowflake appeal is well underway and this year invites you to sponsor a snowflake in honour or memory of loved ones.

We are enjoying looking at your snowflakes and reading the stories and messages behind them.

The appeal is open until 31st December and so plenty of time to sponsor your snowflake. See our Facebook page or website for the link.

Your donations to the snowflake appeal help us to continue supporting families affected by a CDH diagnosis and outcome.





Christmas Puzzle



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Rearrange the individual letters highlighted in the blue boxes above to create a the name of a very happy chappy below.

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Word Search

Find Santa's
Reindeers' names

blitzen dancer dasher donner
comet cupid prancer rudolph
vixen reindeer



d	a	s	h	e	r	c	x	u	o
a	z	g	l	y	e	o	h	j	n
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o	r	m	l	e	c	u	p	i	d
n	x	p	b	p	v	w	l	e	q
s	h	y	r	e	c	n	a	r	p

Useful websites

ARC Antenatal results and choices
www.arc-uk.org

Asthma UK
www.asthma.org.uk

Bliss - Baby Life Support Systems
www.bliss.org.uk

Bounty - Support for new parents
www.bounty.com

British Heart Foundation
www.bhf.org.uk

CDH UK is a member of Rare Disease UK
www.raredisease.org.uk

CDH UK webshop
www.giveasyoulive.com

Child Bereavement UK
www.childbereavement.org.uk

Contact
www.contact.org.uk

Ebay for charity CDH page
www.charity.ebay.co.uk/CDH-UK/125342

Medical Research Articles
www.bmj.com

Scoliosis Association (UK)
www.sauk.org.uk

Stillbirth And Neonatal Death Society (SANDS)
www.uk-sands.org

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Hernia Charity