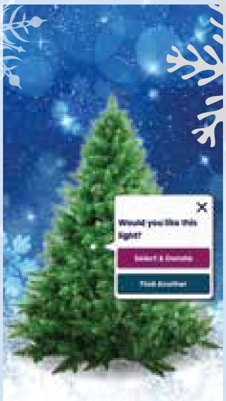
The CDH Magazine

EDITION 6 2025

In this year's annual magazine, we warmly invite you to discover more inspirational stories from our CDH UK families, as well as updates on vital research and the wonderful fundraising activities making a difference.

Thank you to CDH UK from Ezra & his parents

Snowflake Appeal 2025



This year we have our virtual tree for you to decorate!

For a donation you can choose a decoration in honour or memory of someone you love. **All proceeds less set up costs and fees come straight to CDH UK, find the link on our website and social media accounts.**

CDH Community Conference (CCC)

Families enjoyed engaging with the presentations and sharing experiences and children were treated to some creative activities and made new friends **…one of them being the GOSH bear!**

cdh UK
The Congenital
Diaphragmatic
Hernia Charity

Chairperson's welcome

Welcome to the 2025 edition of The CDH magazine!

Inside this edition you will find inspirational stories, updates on research and other activities undertaken by CDH UK to support families, clinicians and researchers.

As Chairperson of CDH UK I am always delighted to be involved with editing the magazine and to have the opportunity to read your stories, they really do help families to understand the condition better and where to obtain further information and support. They also help us as a charity, to understand how we can improve our services and resources. Remember that we are always here to support you, even at this time of year when some families struggle more than usual.

cdh UK The Congenital Diaphragmatic Hernia Charity

This year it will be sixteen years since I started volunteering for CDH UK and I have enjoyed it immensely. Not only am I helping to give back and support future families, but I have also learned new skills. It is a very rewarding experience in my opinion and one that you may also like to try. We have various roles for volunteers to consider, allowing you to decide how much time you choose to volunteer. We always welcome new committee members too, to help us run the day to day affairs and activities of CDH UK.

To find out more please contact us by emailing **committee@cdhuk.org.uk**

I hope you enjoy the magazine as much as I enjoyed editing it! So that just leaves me to thank all of our wonderful team for their hard work and commitment this year, our donors for their support, and last but by no means least, to wish you all a peaceful Christmas and a wonderful New Year!

Bev x

Impact Statement 2025

2025

Impact review

cdh UK 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.

28 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 £900,000 DONATED TO RESEARCH

We grew our Research fund even more during 2025 to add to our already amazing total above! We hope to grow this further in 2026 and contribute even more!

4000 HOURS

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

over 12 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

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.

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

CREATED BY
CDH UK - The congenital Diaphragmatic Hernia Charity

CDH Research HUB

During 2025 we have granted further funds to projects based at UCL and Bristol. The project at UCL focuses on predicting outcomes better during pregnancy.

The Bristol project is looking at CDH surgical outcomes.

We have also collaborated on projects with ERNICA and CSOR which also focus on surgical outcomes.

We were very honoured to have been invited to speak at the 2025 European Paediatric Association (EUPSA) Congress. Our Chairperson Beverley Power spoke about the importance of patients and Clinicians working together for improved outcomes.

You can find out all about our past research funding and collaborations and read about the latest exciting research by visiting the research hub on our website.

You can also donate via the donate button to help us to continue to fund research.

Bev & Team

cdh UK
The Congenital
Diaphragmatic
Hernia Charity

Collaboration Ernica

CDH UK continues to be an active member of ERNICA-European Reference Network for Inherited and Congenital intestinal and abdominal wall anomalies. Each year we attend the annual meeting for a round up of activities and progress.

From Wednesday 2nd to Friday 4th April 2025, the 9th ERNICA Network Meeting was hosted by Frankfurt University Hospital, Germany. The event brought together ERNICA full members and affiliated partners, patient representatives and stakeholders to discuss ongoing initiatives, collaborations, and strategic developments.

On Wednesday afternoon, ERNICA hosted its inaugural Artificial Intelligence Session, marking a significant step toward exploring the role of AI in rare disease networks. Sebastian Tschauner opened the session with an insightful overview of current advancements in AI. Rosa Verhoeven followed with a thought-provoking discussion on practical applications, including how AI can support complex ethical decision-making. Holger Till, co-lead of the ERNICA AI Taskforce, concluded the session by presenting key findings from the recent ERNICA AI Survey. The event drew a full room of engaged onsite participants, along with remote attendees, and sparked lively and meaningful discussions.

Running in parallel, the EPSA-ERNICA Board Meeting was held, providing an update on the status of newly connected hospitals and the continued development of the EPSA-ERNICA registry. A demonstration was given on a newly developed Exploratory Dashboard, which allows connected centres to view and analyse their own data. Centres were encouraged to explore their centre-specific results within this dashboard.

Additionally, the Codman Connect feature was introduced. This feature facilitates collaboration between healthcare institutions by enabling them to share quality-of-care information and benchmark their outcomes against one another. If you're interested in using this feature between centers, please feel free to contact the EPSA PM team (Marlinde van der Kamp and Romee van Steekelenburg).

The meeting also addressed the topic of data sharing for research purposes. It was emphasised that data verification must take place prior to opening the dataset for research.

The session concluded with a warm welcome to the newly elected Clinical Advisory Board (CAB) members (Tomas Wester and Krystian Toczewski).

Later in the day, the Transversal Working Groups on Transition & Adult Care and Quality of Life met to discuss upcoming webinars, planned activities, and ongoing research studies.

The ERNICA Scientific Committee, co-chaired by Roel Bakx and Francesca Russo, also convened to discuss the research updates of the different working groups. Moreover, the recipients of the first ERNICA Travel Grant for Young Researchers were invited to pitch their projects to the committee.

cdh UK The Congenital Diaphragmatic Hernia Charity

Collaboration Ernica (continued)

The Central Implementation Support Team (CIST) reviewed the outcomes of the baseline studies and outlined next steps for ERNICA's implementation activities.

Finally, the ERNICA Board Meeting, chaired by ERNICA Coordinator René Wijnen, covered several key updates:
the ERNICA Grant, including the current budget and available funding; ERNICA Project Management team capacity; progress on the ERNICA member performance system and CPMS; and an update from the patient representatives (presented by Anke Widenmann).

On Thursday 11th April, the plenary program was opened with a warm welcome by the local representative,Udo Rolle, and the ERNICA coordinator, René Wijnen. René Wijnen reflected on ERNICA's key achievements since the last Annual Meeting and shared the plans for the 2025-2026 period. This was followed by a presentation from Olivia Spivack, who provided an update on ERNICA's ongoing implementation activities. The introduction was concluded by Michal Rygl, centre representative from Motol University Hospital, who officially announced that the next ERNICA Annual Meeting will take place in Prague from 25-27 March 2026.

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.

Freddie's Story

Hello!
I just wanted to share my story of my little boy, Freddie Rhys Jones who unfortunately passed away at a week old on 04/07/2025.

On the 7th of December 2024 I found out I was pregnant. I've never been so excited about anything in my life. When you find out you're pregnant and reach the 12 week mark, you don't even think about the possibility of anything being wrong.

I had my 12 week scan at 13 weeks, baby looked perfect.

Then, at 20 weeks, the sonographer doing my 20 week scan spent a very long time looking at Freddie. At the end, she told me she needed to talk to me about my baby's heart. She said the left side was small and blood wasn't flowing properly and to prepare myself as he wasn't compatible with life. I was sent to my local Fetal Medicine Unit 2 days later. Those 2 days filled with dread.

I left the Fetal Medicine Unit extremely happy, as they told me she was wrong and that there was absolutely nothing wrong with my baby! I couldn't believe someone could get it so wrong!

After the good news, I decided to start Freddie's nursery. I made it perfect. He had absolutely everything. Then, at 24 weeks, I started bleeding a little. I went to the local maternity assessment unit where they decided to give me a scan just to make sure everything was ok.

They took me down and this sonographer asked me what happened at my 20 week scan, so I explained. I could see on his face that something was wrong. I asked him to please tell me and just be honest as I'd had so much heartbreak already.

He explained to me that my baby's bowel was in his chest and his heart was being pushed right over to the left. He said he would send me back to Fetal Medicine and then we can decide if there's any compatibility with life. I was yet again broken.

I couldn't believe that I'd had bad news, then great news, then even worse news in the space of a few weeks.

At the Fetal Medicine Unit, they agreed with my local hospital and sent me to Liverpool's Fetal Medicine Unit so they could tell me more. They said Liverpool would now be in charge of my care.

When I arrived in Liverpool, they were all very lovely. When they started the scan, they could see straight away that my boy had bowel and liver in his chest and that we were dealing with right sided CDH. I was offered an amniocentesis, which I did take. Everything came back fine from that. I had lots of follow up scans and eventually had a Multi-Disciplinary Team Meeting, where I met with surgeons, neonatologists etc that would be working with Freddie. I was offered a Termination for Medical Reasons here, which I declined. I had to give him some kind of chance.

Freddie's Story (continued)

I carried on as normal-ish as I could. I did take my Maternity Leave early from work so I was available for all my appointments (I live in Wales so had to travel for the majority of them).

Eventually, on Sunday 22nd of June, my baby shower came around! It was a beautiful day full of love and happiness.

That evening, I explained to my mum that I couldn't feel him moving very much and that I wasn't happy. So we went in to the assessment unit.

They monitored me and Freddie, he was doing fine according to the CTG's, so they took me into the examination room and said they wanted to perform a swab, to see if my waters had gone. The test came back positive and I was blue lighted straight to Liverpool, where I stayed until his birth.

By the Wednesday, I was given a scan to make sure he was doing ok and to monitor my fluid level. He was fine, but they said they were waiting on my swab test for Group B Strep to come back to decide my next steps. I then explained to them that I already knew I had this, to which she responded 'we need to get him out straight away'.

They induced me later that night/early hours of the next morning. I tried for 24 hours, but nothing happened. I got to 2cm and I was then taken down for an Emergency C Section.

Freddie's Story (continued)

Freddie Rhys Jones was born at 35+2 weeks, weighing a huge 6lbs 2oz at 06:41am. He let me hear 3 of his little cries.

He was just beautiful. The team got him intubated and sedated and brought him over to me for a quick cuddle before they took him to the NICU in Liverpool Women's. Freddie did absolutely fantastic for his first few days. I got cuddles with him on his second day of life which is something I was told I would never get. On Sunday, day 3, he was transferred over to Alder Hey, ready for his repair surgery the following day.

Freddie had his surgery on the Monday and he absolutely sailed through it. He was doing fantastic. I got more cuddles with him on the Wednesday. He was just perfect.

By the Thursday, Freddie took a turn. He was gasping a lot and trying to fight his tubes. It was a really scary time. That night I stayed as late as I possibly could before heading back to the Ronald McDonald House close by.

Friday morning, I got up extra early. I was with Freddie by 6am. He was doing great! He'd had a brilliant night and his sats were great. I was so relieved!

I went and had some dinner later on in the day and when I came back, they explained to me that they were going to change Freddie's ventilator to and oscillator and that he'd started struggling again.

I had to leave to get my c section dressing removed, but they assured me they'd call me if anything changed.

As I was waiting for the midwife, my phone rang. I knew immediately something was wrong. They wanted me to come back up for a chat.

Freddie’s Story (continued)

I left the waiting room and ran straight back up to my boy. They then took me into the family room and explained there was nothing more to be done and that Freddie had gone extremely poorly, extremely quickly.

I went back and just spent as much time as possible with him. My family came from Wales to meet him.

At around 9pm, they did one last blood gas. The results were bad. The doctor explained to me that my son was dying, and asked me what I wanted to do next.

I let my perfect boy be at peace, knowing he never suffered. Freddie passed at around 11pm in my arms on the 4th of July, 2025.

I got to bath him, dress him, do hand and foot prints and spend precious time with him after he had gone.

The bereavement team came and met with me and took us to the Snowdrop Suite at Alder Hey around 3am. It’s got a little bedroom with a cot and a living area and a lovely outdoor area with water features and benches to just sit with your baby. It was beautiful.

I got to see Freddie every day until his birth and death were registered (on the Wednesday).

I then brought him back to where he should be, his home that day.

I still sleep with his blankets and teddies every night. It makes me feel so close to him.

I’m very grateful for all the support I received before, during and after. And I will spend the rest of my life making my sweet angel proud.

He was just too beautiful for earth.

Kaydee's CDH story

My daughter Kaydee was born with CDH, we had no idea at all. All her scans were normal and nothing showed up.

She was born at home, 2 days after her due date.

When she was delivered her cry didn't sound right. The midwives that were present said that she was fine, and everything was OK. I said no, something is definitely not right. We were taken to hospital to have her checked over.

She was born at 3.31am. We were in the hospital for 6 hours until all her observations were finished. They checked her oxygen levels 3 times and it was low.

It was from there that everything went down-hill and she was needing 100% oxygen. They were working on her, doing different tests that felt like forever. They did a chest x-ray which showed her bowels and her stomach were all up in her chest cavity and crushing her left lung. Her tiny little heart was also pushed over slightly, my heart was broken, I didn't know what the outcome was going to be.

Kaydee got incubated straight away so her tiny little body could rest. She then got transfered to a local hospital where she would have her repair surgery.

Kaydee was due to have her repair surgery done on day 2, but unfortunately her right lung collapsed so the surgery couldn't go ahead until her lung had fully inflated.

Kaydee's CDH story (continued)

On day 5, Kaydee was ready for surgery. Walking down to the surgery doors was so upsetting, then kissing her and not knowing if she was going to make it through.

Her surgery was going to take up to 6 hours. My strong princess warrior was out in 3 hours. The surgery had gone well. Kaydee remained incubated so she could recover peacefully.

On day 13, they started to slow her medication down that was keeping her asleep.

She slowly started to wake up. Seeing her move and sticking her little tongue out made me break down. I felt like the luckiest person on the planet.

On day 15, she was fully awake and had her tube removed. She was put onto an airflow machine to help keep the entrance to her lungs open. She also was given a feeding tube so she could slowly be fed. She started off with taking only 9mls of milk.

She started to make good progress and was moved down to a room that was less intensive care. We spent 4 days in that room until we got transfered back to our local hospital. We spent a further 2 weeks in there, as Kaydee needed weaning off all the morphine that had accumulated in her tiny body. She also needed help feeding as she wasn't gaining the body weight the doctor's wanted her to. She got put onto a high calorie formula to help her.

Kaydee's CDH story (continued)

On day 31, we finally got to take our little miracle home. I have to say that was the best day of my life. Kaydee will be 2 years old on the 28th of December and she is doing absolutely amazing. We have regular appointments with the respiratory team, we are so blessed to have her here with us.

Before we had Kaydee we never knew about CDH and to be honest I don't know half the things children can be born with, it has definitely opened my eyes.

My heart absolutely breaks for all the families that have lost their babies to CDH, just to know my heart goes out to you all.

I will continue to spread awareness about CDH and do all I can to help this amazing team.

DISCLAIMER:
The information in this magazine is not to be substituted for medical advice. Every child is different and you cannot compare the progress of another child with CDH to the progress of your own child.

Cody's CDH story

A Journey of Strength, Survival, and Hope

By Theresa, Cody's Mum

Cody is my one and only child, my brave CDH survivor.
For years I had wanted to be a mum, and being in a same-sex marriage, it wasn't easy. At 21 years old, I fell pregnant with Cody, and I was beyond excited to finally be starting my journey into motherhood.
To reassure myself, I paid for private scans at 16 and 28 weeks. Everything seemed perfect. At 16 weeks we found out we were having a boy, and every scan confirmed that he was a healthy little baby.

The Day Everything Changed

At 39 weeks pregnant, Cody wasn't moving much at all, and something inside me told me that something wasn't right.
I went to the hospital for a scan. While the sonographer was scanning me, they had to call in two more specialists. That was the moment our world changed.
We were told they believed Cody had Congenital Diaphragmatic Hernia (CDH) and that we needed to go to Sheffield for an official diagnosis. The next day, it was confirmed, Cody had left-sided CDH. We were told he had only a 50% chance of surviving and we were even offered a termination at 39 weeks. Without hesitation, I refused, as to me it wasn't my fight, it was Cody's.

Fear, Waiting, and Holding On

There wasn't enough time to complete all the scans they needed before he was due. That week passed in a blur of hospital visits and overwhelming fear. We managed to get an MRI scan done, but it had to be at the cancer hospital in Sheffield, as it was the only place available that could do one at such short notice.
During the scan, I completely broke down, with my wife trying her best to comfort me.

Cody's CDH story (continued)

A few days before my due date, a plan was put in place for me to be induced at 39 weeks and 6 days. At that point, his survival chance had risen slightly to 60%. I stayed calm until I was shown to my hospital bed. As the midwife began taking my observations, I broke down in tears. I wasn't scared for myself; I was terrified for my baby boy. I wished for it to be me suffering not my unborn baby boy.

Cody's Arrival

In the end, I needed an emergency caesarean, and Cody was born on his due date. He let out the tiniest cry before being rushed away to be put on a ventilator. I didn't get to see him. My wife managed to take a few photos, and a kind midwife gave me a photo of Cody. It was so hard to not be able to see him.

The next day, I was taken to see him. Seeing him covered in wires, so small and still, was heartbreaking. The only thing I could do was gently hold his tiny hand. Thankfully, he had settled well during his first night.

At just two days old, we received devastating news. A baby girl who also had CDH, and had been recovering at Sheffield Children's Hospital had sadly passed away. I had met her parents the week before during a hospital visit, when a doctor was explaining what would happen to Cody, where he would stay for his operation, and where he would recover. To this day, I still tell Cody about the little girl who went before him, who fought so bravely, and who tragically lost her life to CDH.

The Fight for Surgery

After a couple of days Cody was ready to be moved to Sheffield Children's Hospital just down the road for surgery, but there were no beds available. Over and over again, beds would open then be taken before the ambulance to transport for Cody could even arrive.

Cody's CDH story (continued)

I fought with everything in me for Cody to have the operation he had been ready for since he was just two days old. I remember speaking with the team in charge of his care, including the surgeon who would later go on to save his life.

I told them that while he was lying there, ready to be operated on, he couldn't truly begin his life until he had this life-saving operation. They agreed that if a bed didn't become available soon, they would carry out the operation in the same operating theatre where I had given birth just a few days earlier.

Later that very same day, a bed finally became available and he was transported to Sheffield Children's Hospital that night.

Letting Him Go Without Me

The next morning, I was still in the hospital where I had given birth to Cody, waiting to be discharged so that I could go to Sheffield Children's Hospital to be by Coyd's side. The surgeon who was about to operate on him phoned me and asked if it was okay to go ahead with the operation that morning, even though I wouldn't be able to see him beforehand. Through tears, I told them to go ahead without us.

I couldn't let anything delay his chance at life. We knew he couldn't truly live his life until he had this operation, and I didn't want to be the reason he had to keep living like a doll. The operation was a success, and that afternoon we were finally by Cody's side as he began his recovery.

Two days later, he was taken off the ventilator. Hearing him cry for the first time filled me with overwhelming joy and relief. Cody had fought so well against one of the most deadliest birth defects that sadly takes 50% of babies born with it.

Coming Home

Every day he grew stronger. The first cuddle. The first feed. Every single moment is a memory I hold close to my heart.

After a month of being in hospital, we finally got to take Cody home after being told he could possibly be in hospital for months, we got him home just in time for Christma., I couldn't have asked for a better present, being able to take our little boy home and finally start living as a family.

Twelve Years On

Fast forward 12 years later, Cody is 12 years old and in high school. To look at him now, you would never know the battle he faced at the very start of his life. He still suffers with acid reflux and was diagnosed with asthma a few years ago. He continues to attend yearly appointments at Sheffield Children's Hospital. Academically, he is exactly where he should be, and as a person, he amazes me every single day. I could not be prouder of the young man he is becoming.

I feel so blessed to have my boy by my side and I couldn't be more grateful to Sheffield Children's Hospital, the surgeon who saved Cody's life, the support from CDH UK, my family and friends, and the other incredible families of CDH children of all outcomes.

Thank you

from Ezra & his parents

"We just wanted to write a few words expressing our thanks for the support and resources that you have provided us throughout our journey over the past 3 years.

We were directed to your website just after the 20 week scan that informed us that our baby had severe RCDH with around a 10% chance of survival.

As soon as we reached out you were truly amazing, the info pack you sent us was really helpful in explaining his condition to our families.

We went to London for the FETO surgery, and our little boy was born in July 2023.

3 months in NICU, and many other days in Koala Unit at NMGH.

His NG just came out a couple weeks ago, and we can finally say, after a long journey, we are about to be signed off by all the specialists!

Ezra is a healthy growing boy, with a great sense of humour and enjoying life to the fullest."

Douglas' CDH story

Douglas' first 48 hours.

Our first child, Douglas, was born at our local hospital in January 2022, weighing 6lb 9oz. Moments after his birth, doctors rushed him away because he was struggling to breathe. While my wife was taken to recovery, I was told he had been moved to the hospital's small but exceptional NICU - a place we hadn't even known existed.

After making sure my wife was okay, I went to find the NICU. The doctors brought me onto the ward, and there was our baby - intubated and covered in tape and wires.

The consultant, knowing how overwhelmed I was, explained that after hours of uncertainty, an X-ray revealed a right-sided Congenital Diaphragmatic Hernia (CDH). Later, we learned he was the first case the NICU staff could recall. I was then asked to break the news to my wife, but unable to fully comprehend or articulate what I'd just heard, I asked the consultant to come with me. After my wife had been informed, we visited our baby and were asked to give him a name.
We chose Douglas.

After several hours of preparation, Douglas was transferred by blue-light ambulance to St Mary's NICU - a place that would become our home for the foreseeable future. My wife was admitted to the maternity ward, and I was given a bed beside her.
We managed a few hours of sleep, reassured that Douglas was alive and in expert hands.
The following day, we began learning the NICU routines and rituals that would soon feel second nature - washing our hands, signing in, using the expressing rooms, understanding the equipment and tube feeding.

Douglas post-surgery on day 2.

Meeting our baby again, miles from home, felt surreal. He was so small - a little lion in a plastic box surrounded by wires and machines.

All the beeping and alarms going off, it was overwhelming. In those early hours, we read about CDH: a condition affecting roughly 1 in 2,500 births and accounting for about 8% of major congenital abnormalities. We couldn't believe this was happening to us after such a straightforward, 'normal' pregnancy.
We met the incredible staff caring for him around the clock and learned their routines too - cleaning him, taking bloods, monitoring his vitals - while he lay with his eyes closed. We were taken into countless rooms for meetings to understand the severity of his condition.
His survival odds were 50/50.

Douglas' CDH story (continued)

The surgeons, impossibly kind and humble, told us sooner was better to compete the surgery and on day two, Douglas went into life-saving surgery.

Those first days were a blur of shock and isolation.

Explaining his condition to others was nearly impossible. The best I could manage was: "He was born with his bowel and liver in his chest—which still sounds unbelievable. While Douglas was in surgery, we walked to a nearby café, feeling like we were abandoning him and consumed by anger and sadness. We should have been starting life as a family of three at home, like all our friends and family had done before us. Not for one minute did we imagine that on day two of being parents, we would be signing paperwork for our baby to have lifesaving surgery before even being allowed to hold him.

Seven hours later, we were back by his side. The surgeons had opened him up, relocated his organs, and patched the holes in his diaphragm with Gore-Tex. If possible, he looked even weaker than before. All we could do was cling to hope. We asked how the surgery had gone, one of the surgeons replied well, almost routine. The words routine and well, gave me such hope that Douglas was a real fighter and that we would come out the other side of this nightmare and be home in good time. Those surgeons were miracle workers, incredible people - there's no doubt. To this day, specialists, consultants, and GPs are amazed at how well Douglas has overcome the challenges he's faced since birth.

Four years on and Douglas still struggles with eating and depends on medication to control his reflux. We were told early on that he would need therapies for life, and that truth has stayed with us. Because his lungs were so fragile at birth, even a simple cold can turn into a dangerous chest infection, and he's had to return to hospital several times since.
Today, he has a little sister, Imelda, and it wasn't until our first year with her that we truly understood what raising a 'typical' baby feels like. That contrast makes us even more thankful for Douglas - our brave, beautiful boy - because life could have turned out so differently.

We will never stop feeling grateful for the gift he is to us.

Douglas just before his 4th birthday.

Douglas' dad is running a marathon next year to Fundraise for CDH UK. **GOOD LUCK!**

Harleigh's CDH story

'Like many of us, my CDH journey started at the anomaly scan I had at 22 weeks. The first thing they noticed was that my daughters heart was on the wrong side. From there, we were seen at fetal medicine in my local hospital, who confirmed CDH, and transferred us to another hospital.

The emotional toll this took on me and my partner was BIG. From that first appointment (24 weeks), we were told to expect a very sick child and that I already had two healthy children at home and that she could be very disabled. We were offered a termination at that point, to which we both objected, but told we had time to think about it. From there, we had regular scans monitoring what organs had moved up.

Harleigh was born via emergency Caesarean and intubated straight away. She was stable enough for surgery at 3 days old and found to have liver and spleen up. She had a large patch repair. I haven't got an exact timeline for everything as our time in the NICU was a traumatic blur. But on her first attempt at being extubated, we had a couple of hours with her seemingly doing well, and then things went bad very quickly, and we almost lost her. She was intubated again. 2nd attempt of being extubated went much better, and she went straight onto CPAP and progressed from there, and worked on feeding.

We managed to take our girl home just before a month old and she's now a generally healthy 4 1/2 year old, due to start school in September. She's currently has some difficulties with her swallowing and bowels, which she is medicated for and monitored, but she's doing so well and you wouldn't know the start she had in life by just looking at her.

She recently had her first dance exams and passed. These milestones are a blessing for us, and we are ever so proud of our girl '

Delilah's CDH story

My daughter Delilah Hope Grant was born sleeping on the 4th of June at 12:24pm. I was around 26 weeks pregnant when she was born.

Luckily I got to spend some time with her at the hospital, which will be a memory I'll cherish and carry with me always.

We found out Delilah may have CDH at our 20 weeks pregnancy scan. I was sent to have further tests with fetal medicine, which is where her CDH was confirmed to be severe. We soon found out Delilah had a low chance of survival and was at high risk. She would have also had a poor quality of life from what they could see. As well as the CDH, Delilah had a hole in the middle of her heart, which along with her cdh, would of caused her problems when she was born and also in her future life. All of the options and outcomes we were given were heartbreaking. Our happiness soon changed to sadness. We wanted Delilah to be in no pain and live a happy, healthy life, but that unfortunately couldn't be guaranteed.

So after many appointments and hard conversations we came to a conclusion…
Delilah was born sleeping and was in no pain and was at peace she was beautiful and was a fighter. ♥

She has changed my life in so many ways as well as my family's. ♥

Her little foot prints made a massive impact on us & she will always be remembered and spoken about forever✨

If anyone has unfortunately lost a baby to CDH, try and find some peace in knowing your baby isn't alone and is with other fighters, and they are all so loved.

I wish anyone who is pregnant or planning to be in the future has a happy and healthy baby.

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 2025, 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!

Thanks to **Kids Planet, Conwy** for fundraising for CDH UK! Managers Emma and Danielle organised a walk along Llandudno promenade with children from the nursery in memory of Freddie Rhys Jones. Well done to all the CDHeroes for involved!

DISCLAIMER:
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Our Fundraising CDHeroes!

'We proudly raised £1000 for CDH UK - the Congenital Diaphragmatic Hernia Charity.

We would like to say a huge thank you to everyone who came and supported us.

This wouldn't be possible without you.

We take great pride in being able to support charities that are held dear to members of our dancing school and their families.'

Thank you Anita Tymcyshyn School of Dance! You are CDHeroes!

Our Fundraising CDHeroes!

Well done and thank you to **Alan Martin and his local golf club** on his fantastic golf fundraising event!

He has raised a whopping **£2768.60**

His Grandson was born with #cdh and can be seen in the right hand picture .

If you would like to host a fundraising event please contact us for an official fundraising pack containing marketing guidelines and free merchandise by emailing fundraising@cdhuk.org.uk

Bev & Team

Support feature

CDH UK offers financial support to patients and families, in addition to other areas of support, which can help with various additional costs, that patients and families may encounter.

We set up our original financial scheme called' Home 2 Hospital' in the early 2000's to help families with travelling costs to and from hospital stays and appointments.

As the charity grew and funds increased, we also added accommodation to the scheme for families who have to stay in London for the FETO procedures, or who can't organise other charitable housing or hospital family rooms when their child is hospitalised. The next scheme to be added was the 'Forget Me Not' scheme, to assist bereaved families with funeral and associated costs such as memorial stones.

Our attention then turned to other costs that could crop up including things like specialist mobility prams and walkers, beds etc. and so our 'Help 4 Home' scheme was born.

The latest scheme to be added is the 'Help 4 Holidays' scheme, designed to assist with additional premium costs for travel insurance and equipment that may be needed for travelling such as portable oxygen and mobility aids. This helps families to be able to enjoy travel and to enjoy time away as a family.

We have supported many families over the years through these schemes and without your support we would not be able to offer this assistance.

Here is what one family had to say.

'I wanted to say thank you for helping Gabriel with his insurance costs through Help for Holidays for our trip to Walt Disney world.

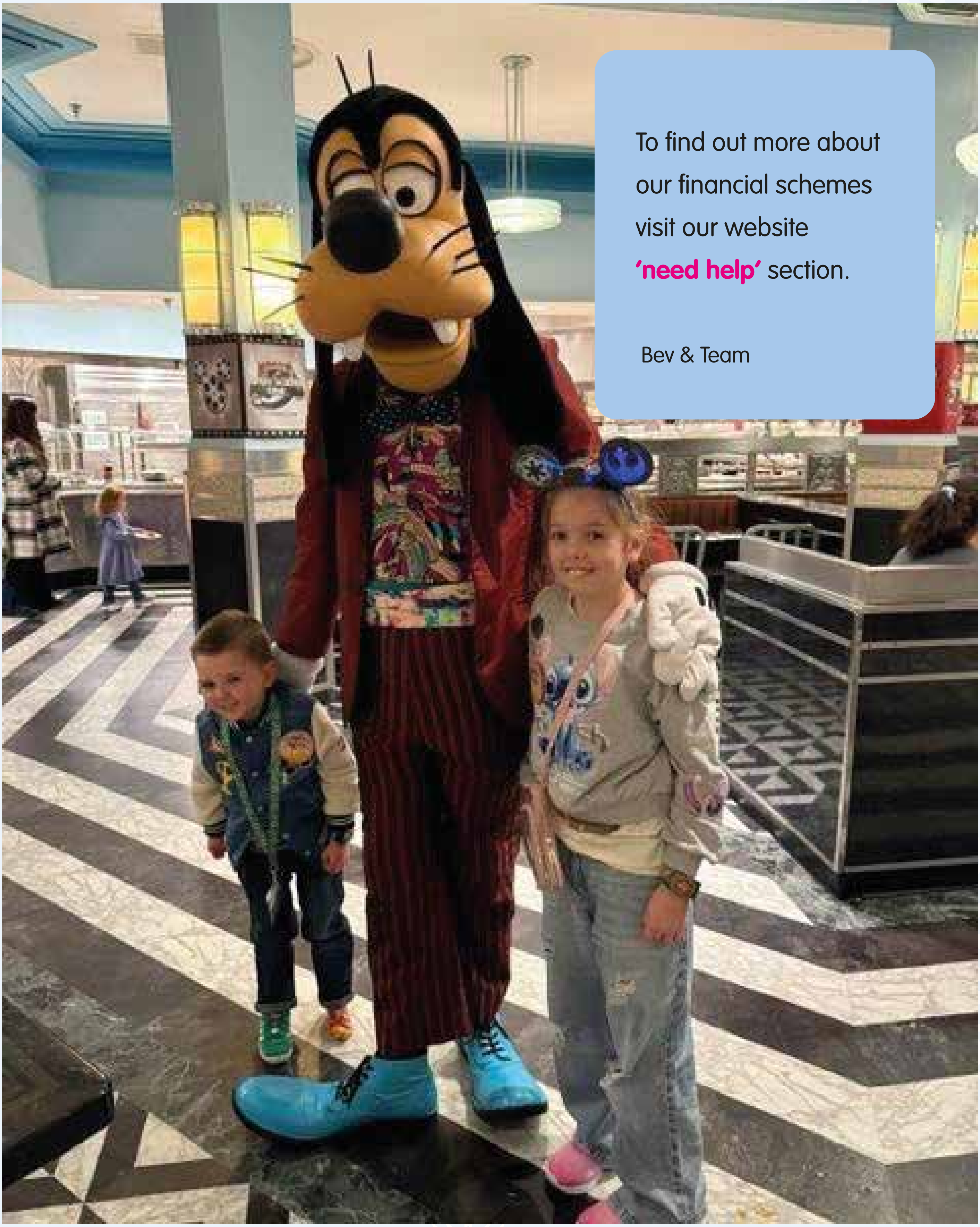
He had an amazing time and has not stoped talking about it.
We wouldn't have been able to afford the insurance on top of the trip without your help.

We have made some incredible memories together and Gabriel got to make his own droid and ride Mickey & Mini's Runaway Railroad.

These were his dreams come true as he watched them thousands of times on YouTube before we booked!'

cdh UK The Congenital Diaphragmatic Hernia Charity

Support feature



To find out more about our financial schemes visit our website **'need help'** section.

Bev & Team

CDH Community Conference (CCC)

Every two years we bring together families, Clinicians and researchers for a day of support, education and research, known as the CDH Community Conference (CCC).

This year we partnered with GOSH UCL Institute of Child Health for our third CDH Community Conference and what a great event it was!

The day ran from 10am until around 5pm and was well attended both in person and virtually. We had presentations and talks from patients and parents as well as the medical community.

Families enjoyed engaging with the presentations and sharing experiences and children were treated to some creative activities and made new friends …one of them being the GOSH bear!

CDH Community Conference (CCC)

(continued)

We heard from an adult patient about her experience growing up and becoming pregnant and also from a Parent who experienced the FETO procedure. We hope to make some of the presentations available to listen to on our website in the new year. Look out for details of our 2027 CCC by following us on social media and eventbrite.

We would like to extend a special thanks to our Patron Paolo De Coppi, Valerie, Mattia and team for helping to organise the day and to our CDH UK team for helping out on the day.

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Awareness 2025

Our official awareness day for CDH is June 28th, but we also raise awareness throughout June using the hashtag JoinInJune4CDH.

This year the theme was all about **'our community'** and how it supports others and helps to raise awareness. We read stories, heard about fundraisers and saw buildings light up!

Here is one of the stories we shared:

#joininjune4cdh

'My daughter (turned 9 on 10th May) was diagnosed at her 20 week scan. I was told she had a right sided cdh. Her chance of survival was at 50%. I had a scan every 2 weeks up until 32 weeks. I was told up until 28 weeks to end my pregnancy as her chances of surviving were dropping. I chose to give her the chance to beat the odds. She was delivered 39+2 by c-section. At 2 days old, I was given the heartbreaking news that the machine weren't gonna make it. That they had done all they could! There was a team coming from a different hospital with a portable ECMO machine but they didnt think she'd survive that long. They came, she flat lined but they got he on the machine. She spent another 4 days stable, where they could do the Hernia repair. She flat lined again, as well as other complications, but the repair was done. The ECMO machine then dislodged and she lost nearly all the blood in her body, and she flat lined once again. But she survived. Against all odds and more doctors telling me she wouldn't make it, she did. She then had her 4th operation at only 10 days old to come off the ECMO machine.

And it was a success!

With that, I was told that during the operation there was some abnormal brain functions and she would need a MRI at a later date to make sure there was no damage. She spent the next 7 weeks in ICU gaining strength and coming off all life support machines. And the looming MRI had arrived, the results showed that there was extensive brain damage and my beautiful daughter would have Cerebral Palsy and wasn't likely to be able to walk, talk and maybe even feed normally! Fast forward to 9 years old and has proven MANY doctors wrong. With a few more operations, complications and scares. She walks with aid, talks fluently and loves food. She loves life and brings joy to everyone that has the privilege to know her.

Not all people get to meet their hero, I'm raising mine!'

Awareness 2025

We hope to see you joining in June 4 CDH in 2026 and please follow us on social media to find out what the theme will be and how to obtain your template to apply for a local landmark light up.

Thank you to everyone who joined us this year.

Remember to show you care and make people aware!

cdh UK The Congenital Diaphragmatic Hernia Charity

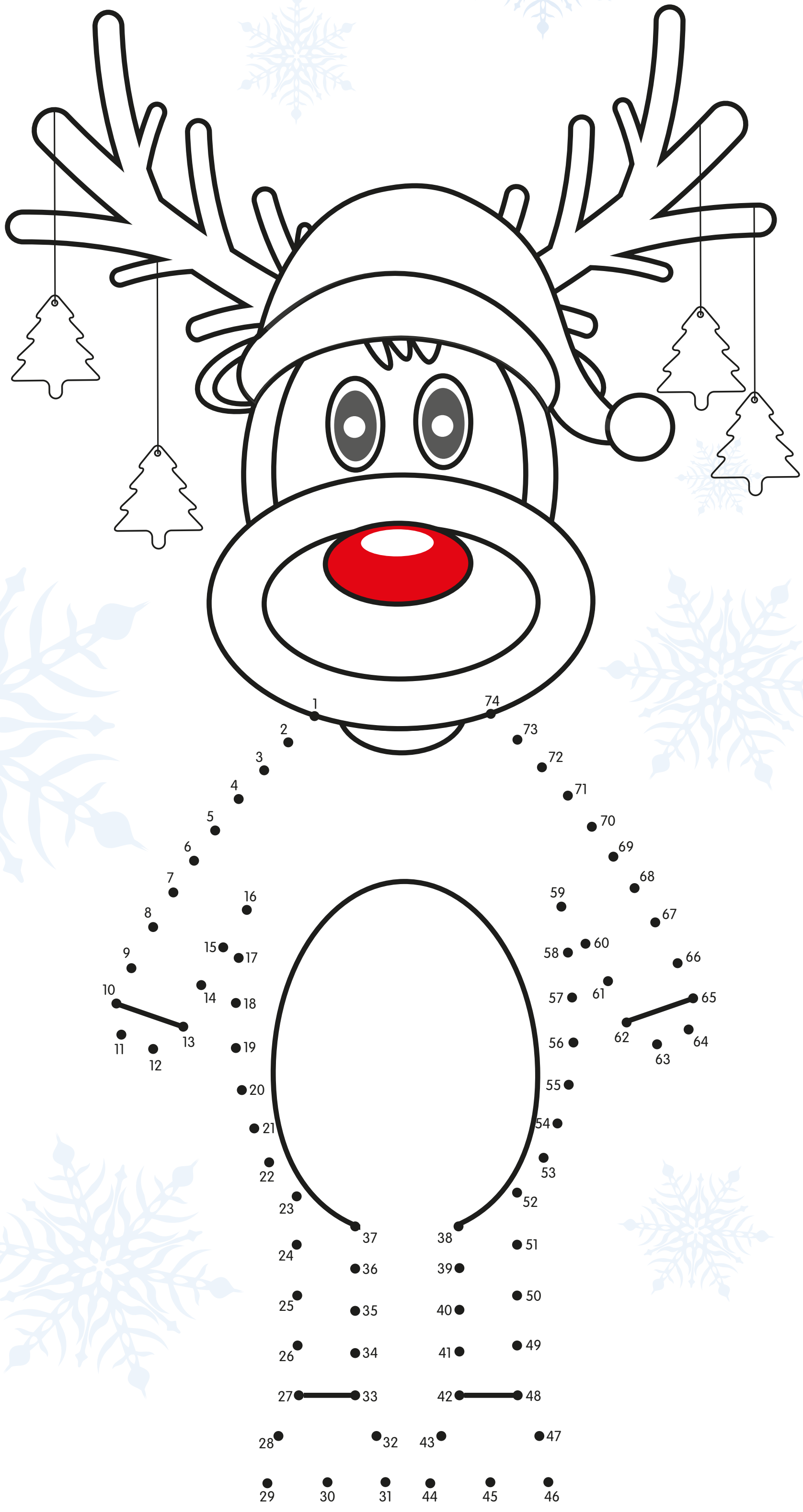
Snowflake Appeal 2025

Thank you to everyone who supported our snowflake appeal last year, your donations help us to continue to support families.

This year we have our virtual tree for you to decorate!

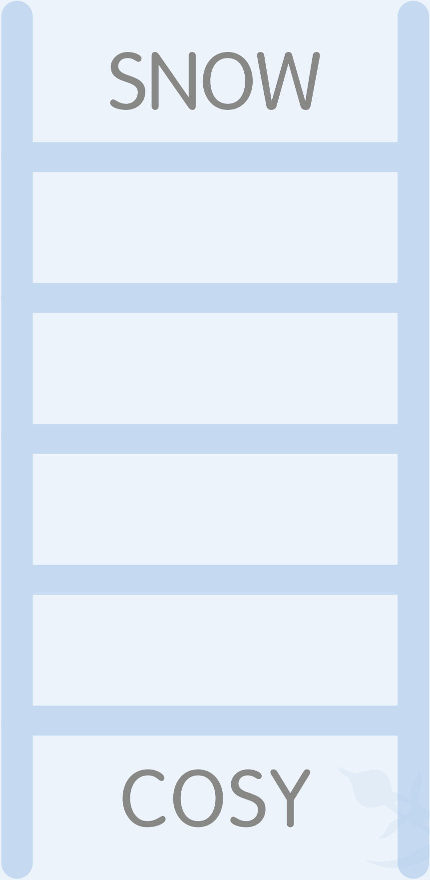
For a donation you can choose a decoration in honour or memory of someone you love. All proceeds less set up costs and fees come straight to CDH UK, find the link on our website and social media accounts.

Join the Rudolph dot-to-dot



Word Ladder

Make your way from **SNOW** to **COSY** by changing one letter on each step to make a new word



ANSWER: SNOW, SNOT, SOOT, COOT, COST, COSY.

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Colour in Christmas Tree

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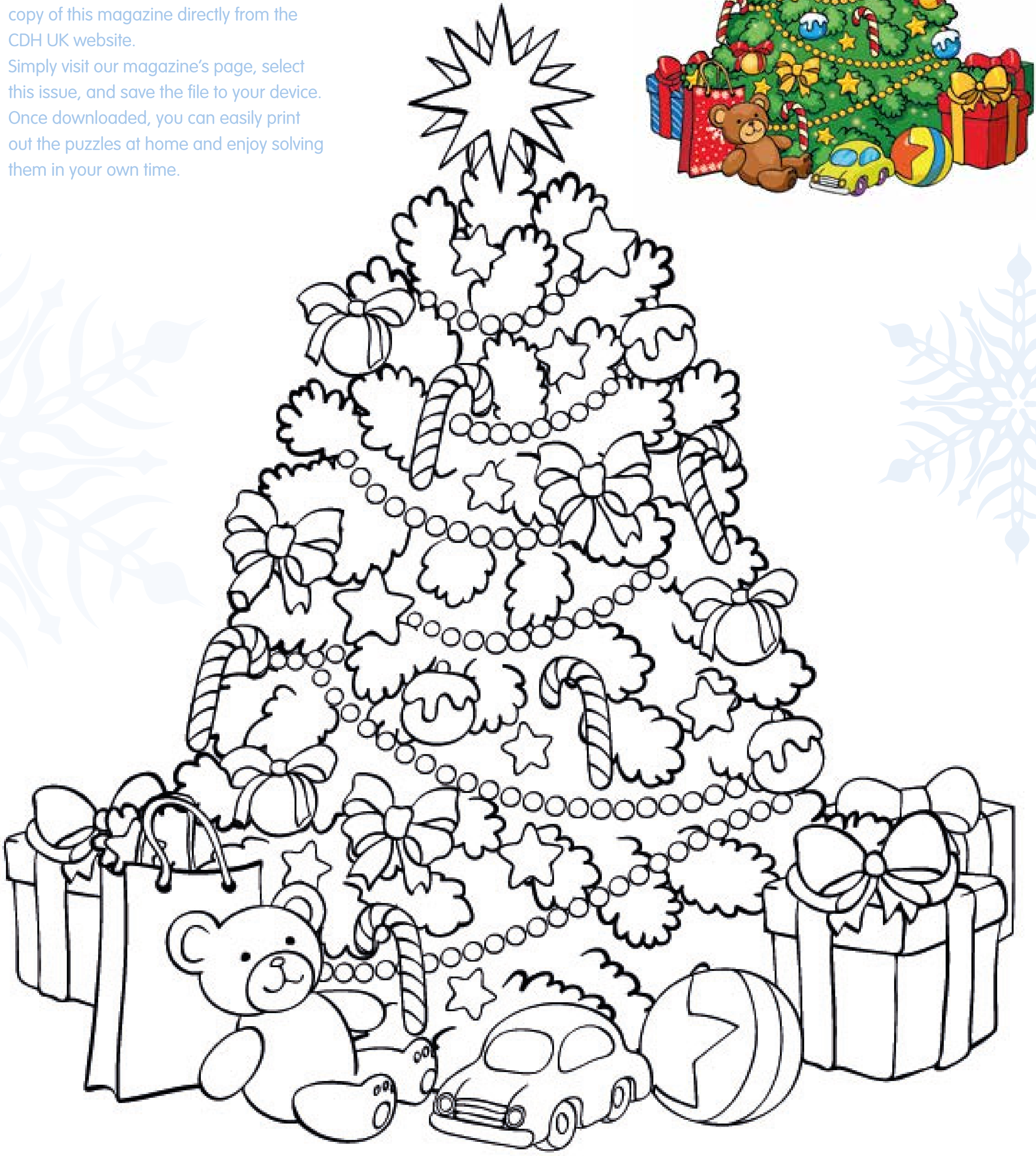

Word Search

Charles Dickens 'A Christmas Carol'

Ghosts of Christmas
Ebenezer Scrooge
Fred
Emily Cratchit
Martha Cratchit
Bob Cratchit
Tiny Tim
Fezziwig
Charles Dickens
Jacob Marley
Past
Present
Future

g	i	w	i	z	z	e	f	s	t	s	t	m	a	s	p	l
e	h	h	p	i	o	n	t	i	g	y	b	e	h	t	f	h
e	i	o	f	l	b	o	b	c	r	a	t	c	h	i	t	e
g	a	t	s	a	p	i	t	y	n	l	g	o	l	h	n	t
o	s	n	n	t	p	b	h	t	h	r	e	h	n	c	y	n
o	l	s	g	s	s	k	g	c	e	a	a	l	e	t	e	s
r	e	s	y	t	h	o	i	r	b	m	m	i	t	a	l	e
c	m	l	s	o	r	n	f	b	t	a	i	s	s	r	r	r
s	d	e	r	f	e	e	l	c	i	e	t	t	i	c	a	u
r	w	a	y	s	l	t	s	m	h	h	y	e	l	a	m	t
e	a	m	w	j	t	n	r	e	a	r	n	n	g	h	b	u
z	m	l	s	g	t	e	o	r	e	p	i	r	e	t	o	f
e	k	c	i	n	a	s	e	r	t	t	t	s	y	r	c	c
n	e	s	n	e	c	e	i	y	n	a	r	f	t	a	a	s
e	m	i	l	y	c	r	a	t	c	h	i	t	a	m	j	a
b	r	a	s	n	n	p	p	b	h	t	h	l	e	h	a	m
e	s	n	c	h	a	r	l	e	s	d	i	c	k	e	n	s

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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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