

The CDH Magazine

EDITION 4 2023

Hello and welcome

Share some truly inspirational stories from our CDH UK families inside this 2023 edition of our annual magazine.



Snowglobe

2 Christmas decorations

ALL THIS FOR A DONATION OF JUST £12

Merry Christmas

A Pack of Christmas cards

Santa hat

2023 CDH UK Snowflake Appeal



Our Fantastic Fundraising CDHeroes!



Chairperson's welcome

I am sitting writing this year's magazine content looking out of my window at a magical winter snow scene over the fields and beyond to the hills.....snow in November where I live! Whilst Winter can be beautiful to look at from the warmth of your home, it also presents some anxiety for CDH families as the Winter viruses come around again. In last year's magazine we did a feature on Winter viruses and illness and you can refer back to this edition and previous ones in the news section of our website. You can also download the magazine to your devices and also print it off for future reference. We hope you find our features helpful and inspiring. This year's picture accompanying my welcome is of me with our founder Brenda Lane at CDH 2017. Brenda has always been an inspiration to me and many others too.

The festive period is upon us, but it can be a difficult time for bereaved families and we have included a feature on getting through the festive period and supporting those who find it difficult. This also includes a section for families of younger children or those families dealing with illness or ongoing medical issues and how to cope with added pressures during this period.



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2023 has been another busy but difficult year for our charity and whilst we have witnessed some amazing fundraising efforts, our donations have declined again this year due mainly to the ongoing cost of living crisis. Our priority in 2024 is to concentrate on new fundraising ideas and new ways to attract support for our work. It is imperative that we keep our financial schemes open to families during the crisis for as long as we are able to do so with your help and support.

We are very pleased to have developed a new information booklet on feeding and this should be published very soon. During the New Year we will be publishing the CDH Patient Journey as a short film to complement our visual graphic. We hope that we can also show this at CDH 2024 in France, which is an event that takes place every two years in a different country organised by The CDH Study Group and The CDH Euro Consortium with input from Patient organisations and ERNICA.

I would again like to thank our amazing team of volunteers without whom we would not exist. We have sadly seen some of them leave during 2023, but for new and exciting adventures of their own and we have happily welcomed new ones. CDH UK is always looking for new volunteers to join our great team and so if you are interested in helping us in 2024 please drop us an email to volunteer@cdhuk.org.uk

Our love and thoughts at this time of year are as always with newly diagnosed families, those families who are bereaved and those in hospital or with unwell children.

We wish you all a peaceful and well festive period and a happy and healthy New Year!

Lots of love Bev & Team

Pictured: Bev Power (left) and CDH UK founder, Brenda Lane (right) at CDH 2017.

Impact Statement

We like to reflect on what impact we have made and so every year we look back on our last year (in this case 2022) and create a quick infographic for you to quick glance at what your donations have helped us to achieve!

2023

Impact review



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!

2nd

Research Publication



We published our second 1st author research paper titled 'The CDH Patient Perspective Journey: to 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 2023 to add to our already amazing total above! We hope to grow this further in 2024 and contribute even more!

MORE THAN

£34,000



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.

3328 HOURS



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

100'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

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

CREATED BY
CDH UK - The Congenital Diaphragmatic Hernia Charity



CDH Research HUB

Last year we issued a call out for new research projects and we were pleased to have received some great applications.

After going through our required application processes, we granted funding totalling to two international collaborative research projects that we are very excited about and we hope will start very soon.

Project 1

The first project is looking into the role the heart plays in CDH and comprises a team of CDH experts from the UK, USA and other European countries.

Project 2

The second project is creating a model of CDH to use as a tool in future research and is headed by a UK researcher and takes place in Canada.

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CDH Research HUB

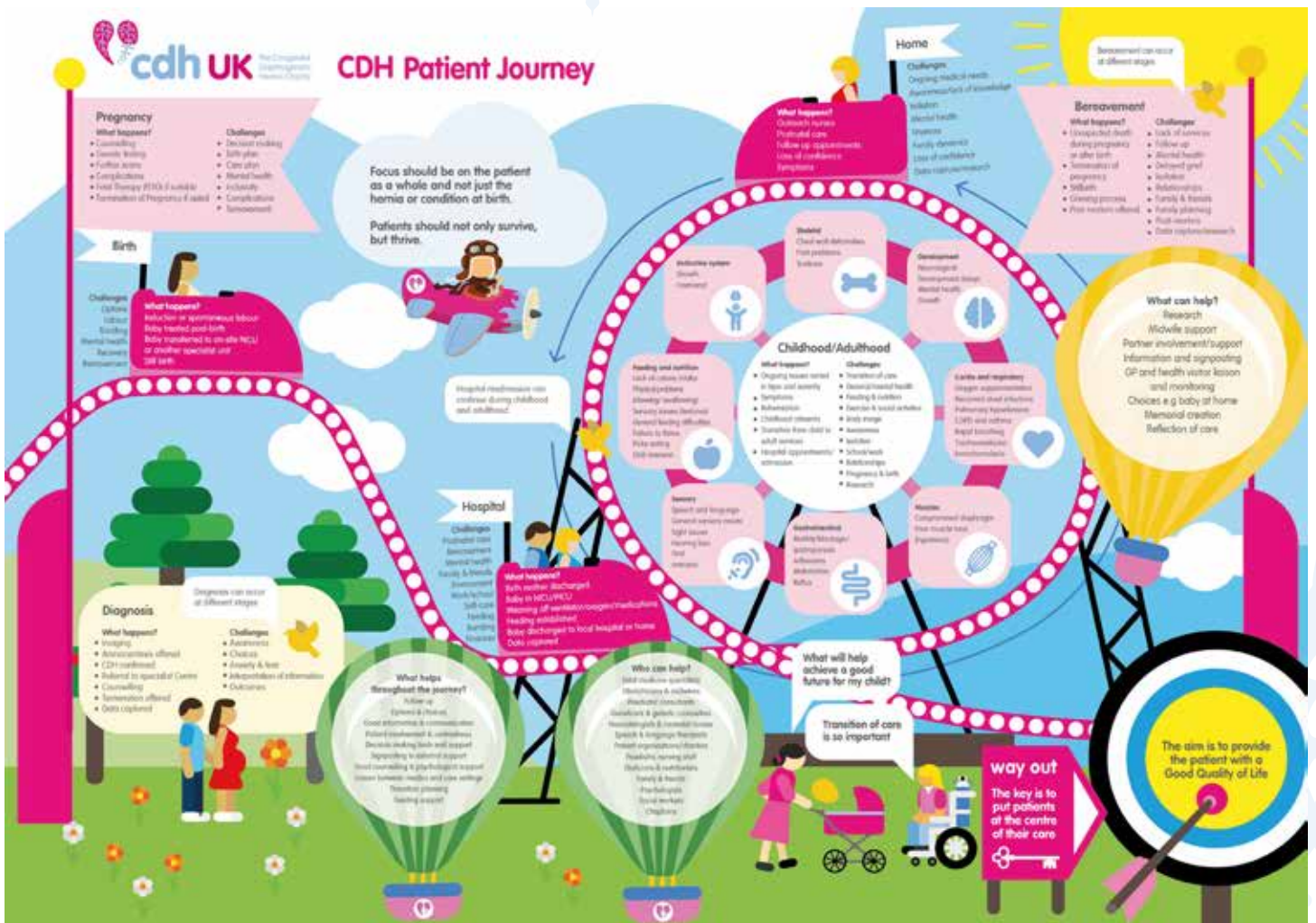
Call out for interested families wishing to participate in research being undertaken in Leeds.

We hope to bring you updates throughout 2024 on this exciting research!

We are also excited for CDH 2024 that is this year taking place in Lille, France and sees experts from all over the world coming together to discuss and present research on CDH. We hope to showcase a new film we are making based upon our published research paper *The CDH Perspective Journey* at the meeting.

Are you a Family with a child diagnosed with CDH before birth and was your baby treated by the Leeds Teaching Trust Hospitals? If the answer is yes they would love to hear from you. Dr Lawrence Miall and colleagues are conducting some important research and if you would like to learn more or you are interested in taking part you can email the neonatal secretaries at Leeds using angela.newstead@nhs.net

We are always interested to hear what research you would like to see being carried out and what you think the priority areas should be. Please let us know by emailing research@cdhuk.org.uk and subject your email **Let's do the right research**



Collaboration **Ernica**

On Wednesday 22nd – Friday 24th March 2023, the 7th ERNICA network meeting was hosted by La Paz Hospital in Madrid, Spain. Our Chairperson Beverley Power presented an update on the CDH Patient Journey and also spoke about Bereavement in CDH. She also had the opportunity to meet again with the founder of the CDH Sverige (Sweden) group who she first met along with other families whilst at the ERNICA meeting in Sweden a few years ago inspiring them to set up a patient group there and then later encouraging them to join ERNICA.



Our Chairperson Beverley Power representing CDH UK at the 7th ERNICA network meeting at La Paz Hospital in Madrid, Spain.

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Collaboration **Ernica**

CDH UK is happy to see the continued research into CDH undertaken by the network and to represent the patient in the scientific committee, pregnancy transversal working group and registries working group.

On Wednesday afternoon, the ERNICA quality of life working group meeting took place, where the group's vision statement, specific aims and plans for coming years were discussed. In parallel, the Gastroschisis guideline development group met to discuss final publication and dissemination of the guideline and next steps for filling identified knowledge gaps. Development of a guideline on Omphalocele was discussed as a next Abdominal Wall Defects group activity. These meetings were followed by the EPSA-ERNICA Scientific Board meeting and the ERNICA board meeting. The EPSA-ERNICA Board meeting provided participants with a status update on the connection of new hospitals to the

EPSA-ERNICA registry, data set revision and user satisfaction and the future of the registry was also discussed. The ERNICA board meeting was chaired by ERNICA coordinator René Wijnen and covered topics including: the implementation of ERNICA Standards of Care, the 5-year ERN-wide evaluation, the upcoming ERNICA grant application 2023-2027, the cross-ERN joint action supporting the integration of ERNs into national health systems and ERNICA governance. Before a group networking dinner in the evening, ERNICA patient representatives had the opportunity to meet each other. This year, ERNICA welcomed three new patient representatives to its annual meeting. On Thursday 23rd March, the plenary programme was opened by ERNICA coordinator René Wijnen and ERNICA project manager Olivia Spivack. Input was collected from participants on their expectations for the ERNICA annual meeting.



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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.

Roman's Story

Here is our brave Roman and his CDH story.

A boy with a right sided diaphragmatic hernia with a type C defect and 11% chance of survival.

We hope it can help you to have hope.

Danielle and Tom, Roman's mother and father.

We found out that our baby had CDH at 35 weeks (December 2022). We had gone to visit a birthing centre as this was where we were expecting to deliver. Thankfully the midwife measured bump and said bump had dropped off the scale, so she sent us for a growth scan.

On Monday 19th December we went for the scan and were told they'd be in contact. We received a phone call to inform us that something wasn't quite right and that they think our unborn baby has a hernia, that he will need an operation once he's born, and that they may want to deliver the baby early. In pure panic, we went and brought premie clothes to be prepared.

The following day we had a follow up scan which started very positive and looked 'normal' but ended with seeing the abnormality, a RCDH (right sided congenital diaphragmatic hernia). We had never heard of CDH before, so we had a lot thrown at us at once and it was so hard to understand it all. At the hospital they did a scan and confirmed to us that the baby's head to lung ration was 90%. So, we had the amniocentesis the same day to see if our baby had any other abnormalities. This all came back clear. Big relief!



We then had to go and see our parents and inform them of our unborn baby's condition which was heart breaking, especially when it was the first grandchild on both sides.

We then were referred to specialist centres that deal with CDH. This was about 1 and a half hour drive away from our home. This is where I then had to go to for all my appointments. Our first appointment there was Thursday 22nd December. I was seen three times in less than a month. We had a few different scans at the specialist Centre where they were unable to get very accurate imaging due to such a late diagnosis, so it was a very unknown situation of how severe our baby was and what the head to lung ratio actually was.

Next stage was to be induced at 38-39 weeks, but we would need to wait for a NICU bed to become free for our baby first.

So, we went in on Friday 13th January to be induced, baby did not want to come so on Monday 16th January I opted for a caesarean section and Roman was born on Tuesday 17th January 2023 at 12:13pm where there were neonatal doctors, consultants, and nurses in the operating room ready for his arrival. He weighed 6lb 6oz. He was intubated and whisked away to the NICU.

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Roman's CDH story (continued)



Roman's dad tried to go and see him around 3pm and was told they were busy trying to get lines into him and they'd call once they had finished. At 10pm that night we still hadn't had a phone call, so we just went up to see Roman. We got to see our boy and he looked so poorly and vulnerable. Nothing prepared us for the way he looked. We both struggled emotionally with this, but my mother's instinct said 'he'll be ok, he's got this'. I don't know how I could say that, maybe I believed this or was just trying to convince myself.

The next day Wednesday 18th January the consultant had chat with us, they were struggling to oxygenate Roman, and she had referred him to be assessed to see if he was a candidate for ECMO at another hospital, and that the hospital would do everything they could to keep him alive until they arrive. The CATs team (Children's Acute Transport Service) arrived and assessed Roman. They told us they'd be taking him and that we could go in the ambulance with him which was a relief as I wasn't sure I'd be allowed a day after a c-section (unsure of if he'll even survive the journey) so I, Roman's mum went to discharge myself and Roman's Dad went to pack all our belongings into the car. From the minute we got outside of the hospital, Roman started saturating better. We were blue lighted and arrived at the children's hospital within 37 minutes and taken to CICU (cardiac intensive care unit) where Roman was assessed over a few days to see if he needed ECMO. As everyday went past, he became less likely to need it.

On Saturday 21st January, Roman was moved to the NICU. From this day to day 19, Roman was up and down. He had infections, a pneumothorax, multiple pulmonary hypertension crisis' and there were times we didn't think he'd pull through.



On Monday 6th February, Roman was strong enough for his repair surgery. He went down at 1pm and we got a call at 18:47 to inform us that the NICU had the call to go and collect him from theatre. The surgeon then called to update us to tell us everything went well, they did it laparoscopy (keyhole) and that he'd speak to us in person over the next couple of days. Roman had a type C defect with 50-57% of his diaphragm missing with his right lobe of liver, right kidney and both collapsed small and large bowel occupying the entire right hemithorax.

We rushed over to see Roman and were warned he may go downhill temporarily after surgery, but he didn't. His tummy looked like it was about to burst, with all the co2 they'd pumped into him during surgery.

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Roman's CDH story (continued)



They aren't lying when they say intensive care is a rollercoaster, it is. We had many ups and down, still suffering with pulmonary hypertension but we were able to wean the pressures and his oxygen. Roman got to go outside the NICU to the Japanese Garden. This was his first experience off the ward and in the fresh air.

Breathing support:

Intubated from Tuesday 17th January until Monday 20th March. Roman was then extubated for the first time. He had 20 hours on high flow on 22% oxygen and then went onto BiPAP as he was struggling. They had to keep him sedated for 48 hours as he wasn't tolerating it. He was then de-escalated to CPAP. His settings were weaned, we moved to high flow in the day and CPAP of a night and then finally onto high flow full time, down to nasal cannula and then off all breathing support from Sunday 7th May.

Feeding:

Roman had the go ahead from SALT to explore a bottle. Thursday 13th April was his first experience. He took 1ml the first time, 3ml the second, 10ml the third, 37ml the fourth time and then the fifth time he took 57ml and the sixth time a full bottle of 97ml. We slowly increased the amount of bottle feeds he was allowed and then moved him over to just bottle feeds, only medications given via the NG.

Medication and withdrawal:

Roman was on lots of medication, quadruple inotropes, fentanyl, morphine, clonidine, sildenafil, omeprazole, and lots of other medications. Chloral was used a lot to help Roman relax and sleep when withdrawing. Withdrawal was one of the hardest parts of the journey. Due to Roman being intubated for so long he had to be sedated which meant he got addicted to these medications. When weaning the medication, we sometimes had to go back up and we were in a vicious cycle. Some days we had to keep him comfortable using other forms of medication to be able to wean the medications. We got through it, thankfully!



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Roman's CDH story (continued)



Local hospital and transferring hospital:

Our local hospital and another specialist hospital didn't have a bed for Roman when he was stable and ready to be transferred for lower-level care. One of the issues was the IV clonidine that nowhere would take. Thankfully for us, we got to stay until Roman was ready to go home. We planned with the consultants, surgeons, and sister nurse to get the ball in motion for Roman to be discharged from the NICU at another hospital which they don't usually do, but we were keeping Roman in hospital waiting for a bed at the local when he didn't need to be. We got to room in with Roman from Sunday 14th May to Thursday 18th June when we were finally discharged.

We were supposed to leave earlier in the week, but the second routine vaccines made Roman poorly.

Coming home:

It was daunting coming home especially after being in intensive care and not being on a ward where there isn't 24-hour monitoring. The hospital did leave us to it and took all the sats monitors off when we roomed in so we could get used to it. We were able to take him off of the premises which was nice. We thought we may need an oximeter, but we haven't needed one. Within a week of coming home, the NG was out, and everything was oral.

Roman slept through the night and was enjoying his time at home. He instantly became a happier baby.

Weight:

Roman left hospital under-weight and not on the centile line but was gaining weight. We had to put an additional scoop of formula into his milk to help with his weight gain. Since he has begun eating solids, it's really helped with his weight gain. We are currently closer to the 25th centile line which is amazing considering where we were back in May, not even on a line.

Graduation:

On Tuesday 2nd May, I'd come off all the drugs and support for me to be able to graduate NICU. Little did we know a bed would not become available but because things can change so quickly and a bed could have become available in the middle of the night, we had my NICU graduation.

Now:

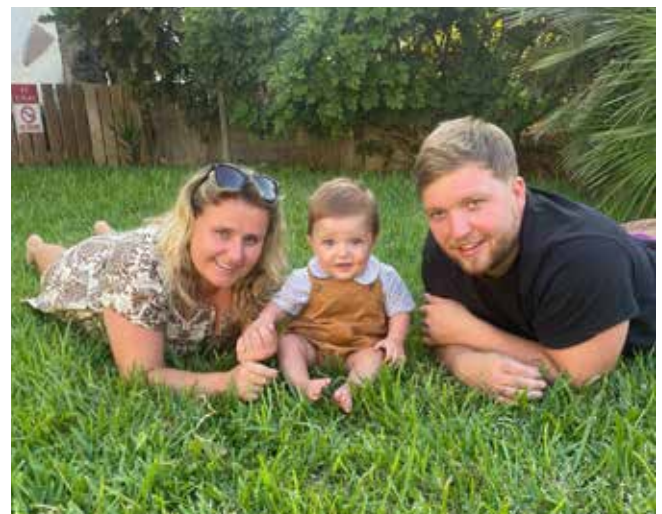
Roman is now 10 months old, meeting all his milestones. He's crawling, pulling himself up, standing up with support and is very eager to walk. He said his first word a few months ago 'mum' and had just recently started saying 'dad'. He's been on UK holidays as well as holidays abroad, he has started swimming lessons, has a new fur puppy as well as his African Grey Parrot who constantly asks 'where's Roman, where's Ro Ro.'

We have regular check ups with the hospital.

Roman is a foodie, loves all food and eats three meals a day, two snacks and up to four 7oz bottles a day.

Roman is due to have another surgery in Spring 2024 for his inguinal hernia.

Thank you to everyone involved in his care and the phenomenal staff and also to CDH UK for their support.



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Winnie's CDH story



Winnie was born after induction this November at Birmingham, I got to have her on my chest for one minute whilst they did delayed cord clamping then she was intubated. Since then, she's gone from strength to strength in no time she was on 21% oxygen and had her surgery. They managed to do it keyhole, everyone was so surprised at her doing so well, she's so far had no need for nitric oxide, or anything. The surgeon spoke to me and mentioned that despite the large amount of bowel and liver in there she has the sac type of hernia! So, the liver and bowel must have been held down for longer.

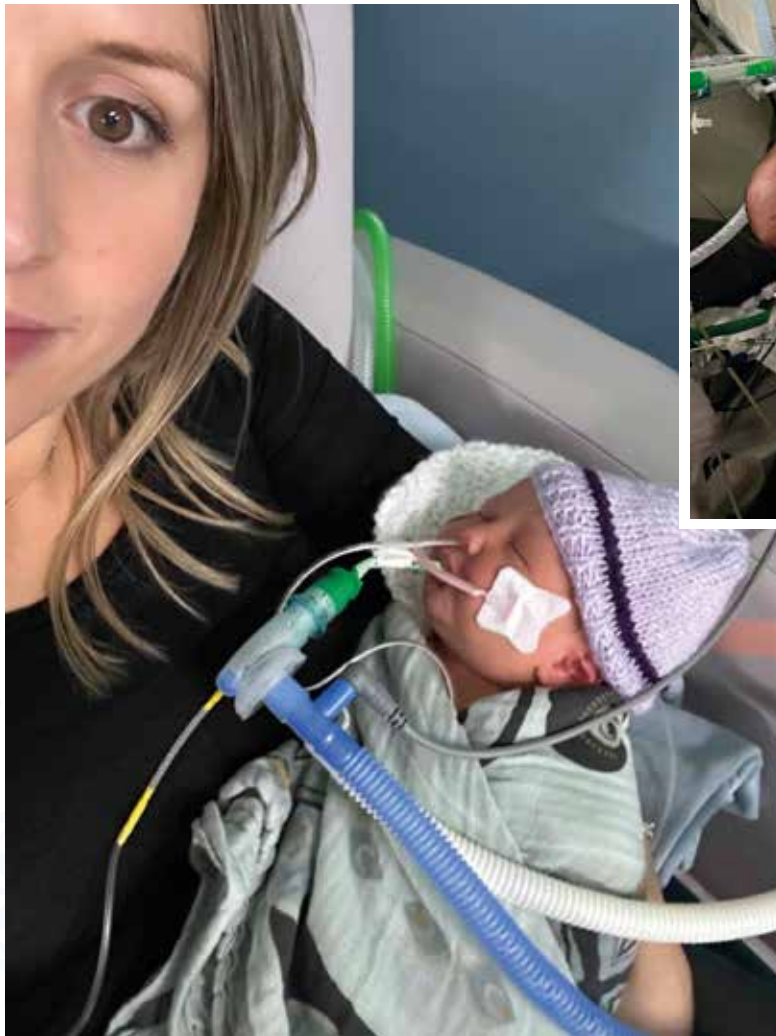


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Winnie's CDH story (continued)

She has right lung tissue which began to inflate about 8 hours after her operation. She's was on 21% oxygen and some morphine; they weaned down the reps on the machine and will keep an eye for fluid in the chest, but basically that membrane/sac has saved her life. She was officially extubated and she's on Optiflow 21% oxygen doing amazingly well so far.



Thank you so much for your support I wanted to share as it's a more unusual story with the rare sac type. Just got to be patient whilst she recovers now but I feel like I've won the lottery.

Love Chelsey and baby Winnie



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Lochlan's CDH story



I didn't find out about Lochlan's CDH until I was 34 weeks pregnant and as you can imagine I didn't have long to process all this new and scary information. Before I knew it I was transferred to a specialist hospital to be induced, which was scary in itself and with finding out so late on in my pregnancy I didn't know the significance to Lochlan's hernia until he underwent his surgery at just 5 days old. With all the luck in the world his surgery went really well and the repair needed was small enough for my tiny human to have keyhole surgery. Doctors were, and still are, super amazed at how far he has come in such a short space of time. We still have a long road to go but I am happy to say that we have been discharged from hospital and finally been able to take 'Our brave boy' home. He has done superb and I am so in awe of his continuous strength.



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Ayra's CDH story



I found out I was pregnant in July 2016 and was over the moon. I didn't know what to do so I booked a GP appointment for the next day and was told I'd lost the baby. I still felt pregnant, so one day in work (I work in a hospital) I was told to go downstairs to A&E due to me bleeding and still feeling pregnant, they scanned me and said the sac was there and to have another scan in 2 weeks.

At the 2nd scan I was told there were 2 sacs, so I was having twins. At the 12 weeks scan I was told that the baby may have Down's Syndrome due to fluid behind the neck, and there was now only one baby. I was told to continue to stay off work as it was a high-risk pregnancy.

I made the decision that I wanted Arya even if she had Down's Syndrome and began looking into it.

After 3 separate attempts at an amniocentesis the results came back as negative for Down's Syndrome and that I was having a girl.

I was so excited but at the back of my mind, having seen the scans from the amniocentesis (I was given a scan picture to take home), I believed that something was wrong still, as there was a black area on the scan in her stomach. I was really worried sitting in the waiting room before the 20 week scan, whilst we were in there Arya was diagnosed with a CDH.

I asked the sonographer what that meant and they said she would need physio once she was born. Having worked in healthcare most of my life I thought, that's fine, I will do whatever it takes to help her and was worried but didn't think it was as bad as what it actually was.

Basically, the sonographer had no idea what it was and neither did my midwife and she continued to treat my pregnancy like any other normal pregnancy.

We were referred to a specialist hospital which, as things progressed, I had to go for many extra scans and checks etc. At one of the scans, I was told that Arya had a cleft palate, scoliosis and microcephaly.

At the next scan, we had a 3D scan and we were told she didn't have a cleft palate. As the pregnancy progressed we were given the worst diagnosis possible....a 0% chance of survival. Her organs from her lower abdomen had risen up into her chest, her heart had been pushed to the right side and was tiny due to not having enough space to grow, also both her lungs hadn't developed properly, one was tiny and the one had hardly grown at all and wouldn't be able to keep her alive.

After each scan we were all taken into a room and always offered a termination, which of course I didn't want. Doctors get things wrong sometimes and I wanted to leave the decision with Arya and give her the chance.

She was doing so well in my tummy that basically I would have just kept her in there forever. Her heart rate was always amazing (considering it was tiny and on the wrong side of her body), her movements were always normal. She used to kick me hard in the ribs with her long legs she always seemed so strong, and she was.

There was always a possibility that she may pass before birth which of course worried me but I felt she was strong. I was told I would need to be induced on a set day and that due to her lungs being so small she wouldn't cry or even get as far as the Neonatal Unit to try and stabilise her.

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Ayra's CDH story (continued)

When I arrived at Hospital, I was already having small contractions due to being full term. But after speaking to the doctors I was booked in to be induced on the Tuesday (a few days away) and when that came round I was induced, but only needed one attempt and she was on her way.

5 hours later she was ready to come out, there were so many people in the room due to her heart rate dropping with each contraction and the midwife thinking her arm was stuck, even though it was her ear (not sure how this caused confusion, as she was only 4lbs 4 oz).

Ayra was delivered, with forceps, at 5.29pm on 28th March 2017. She let out a little cry (even though they said she wouldn't). Arya didn't have microcephaly, a cleft palate or scoliosis and she was stabilised in the room, then whisked away.

I didn't get to hold her yet of course. She was taken away and I didn't see her for a little while. Then we went to see her in the Neonatal Unit (we were told she wouldn't make it to there previously) but once there, they had taken some scans and I was told that she had the worst case of CDH (Congenital Diaphragmatic Hernia) they'd seen.

I held her 3 times through the night and on the 3rd time she passed away in my arms. I chose to not have her tubes removed as I wanted to let her decide when it was time (a choice I'm not sure was selfish or not). She had all of us around her and if love could have saved her, she would have lived forever. She was absolutely beautiful (I know I'm biased) she was so strong and I am so proud of her for staying with us for 16 and a half hours considering we were told she wouldn't make it to the Neonatal Unit. My one and only child, Arya, I will love you until the end of time and I really hope I will be reunited with you one day.

Lots of love, Mummy



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Trinity's CDH story

I found out I was pregnant with my baby on Mother's Day 2023. My partner and I were so happy.



Everything was going so well and we didn't suspect there was anything wrong until we had our 20 week scan. They told us they could see a problem with her heart.

We had a follow up scan to find out what was going on and they confirmed that our baby girl had left sided CDH, which was causing her heart to be pushed onto the right-hand side of her chest and her bowel, stomach and some liver was in her chest. She was also diagnosed at this stage with an AVSD heart defect.

They told us her chance of survival (if making it to full term) was 50%. We had lots of hope and attended fortnightly scans. I ended up developing polyhydramnios (extra amniotic fluid) at around 26 weeks and so I was monitored and scanned weekly. We were warned at this point she has a higher chance of being pre-term and if that happened, she is unlikely to survive birth.

On the 22nd September my water's broke at exactly 32 weeks and I went into labour straight away, resulting in the birth of my beautiful daughter Trinity on the following day, Saturday 23rd September 2023.

Trinity was taken to the NICU and had to go into emergency surgery only a few hours after she was born, because the doctors had trouble getting her breathing and other tubes down her throat. We soon found out this was because she also had oesophageal atresia (OA) and Tracheo-oesophageal fistula (TOF) on top of the CDH.



During the surgery they found out that Trinity had a complete CDH. She had no diaphragm at all on the left side, so in order to repair she would need a full patch. They also found out that on top of her AVSD heart defect, she had a further heart defect called a Hypoplastic Aortic Arch. In the surgery, the surgeons were not able to fix the OA/TOF because of how severe it was.

Unfortunately, they told us because of how severe each problem she had was, they couldn't help her. Despite the odds our beautiful girl stayed with us fighting so hard for 8 days.

She passed away on her daddy's chest. We miss her so much and she will always be in our hearts. We thank CDH UK so much for their open arms, helping to support families like ours in any way they can.



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Our Fundraising CDHeroes!

Marathon medley!

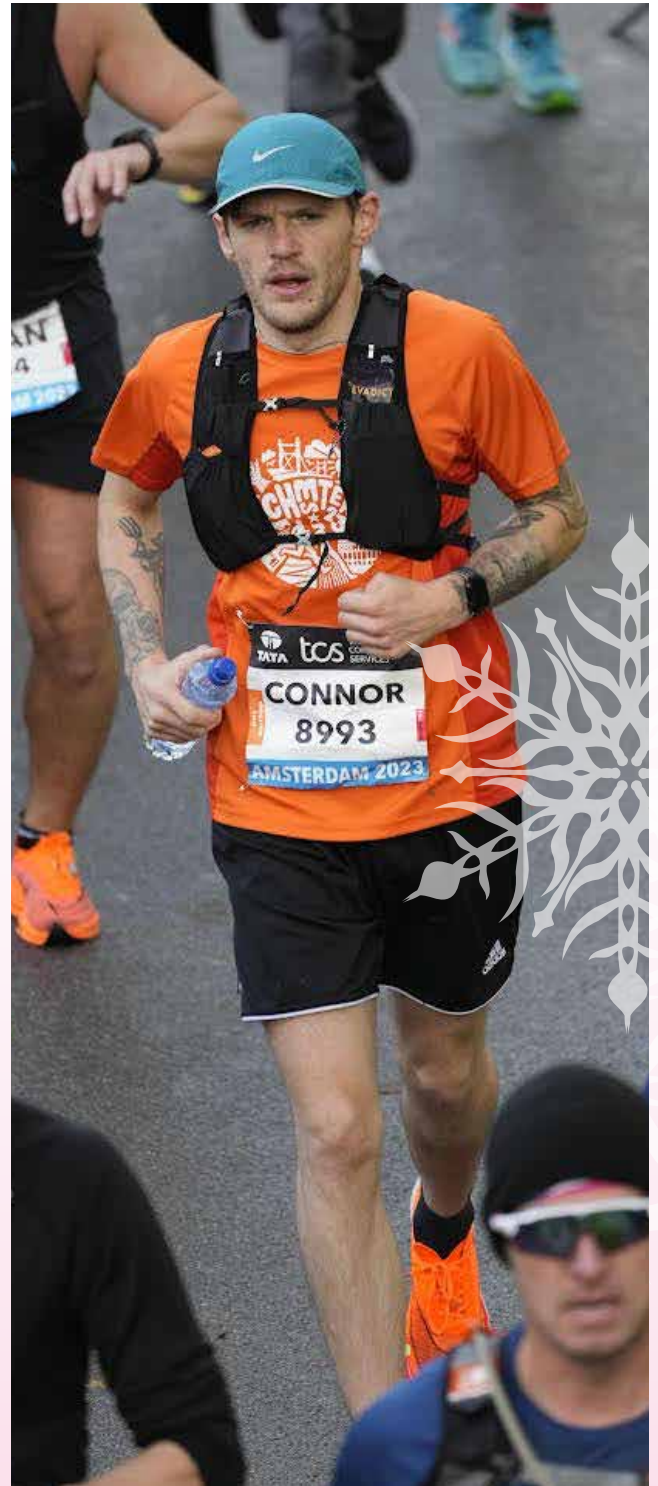


Connor Newton

has been training for taking part in marathons for CDH UK this year.

He has already completed the Amsterdam marathon that took place in October and his next one will be the Manchester marathon in April 2024. Connor tells us that CDH UK means a lot to him and his inspiration is his niece Rosie-Mae who was born with CDH.

Well done so far Connor and thank you!



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Our Fundraising CDHeroes!

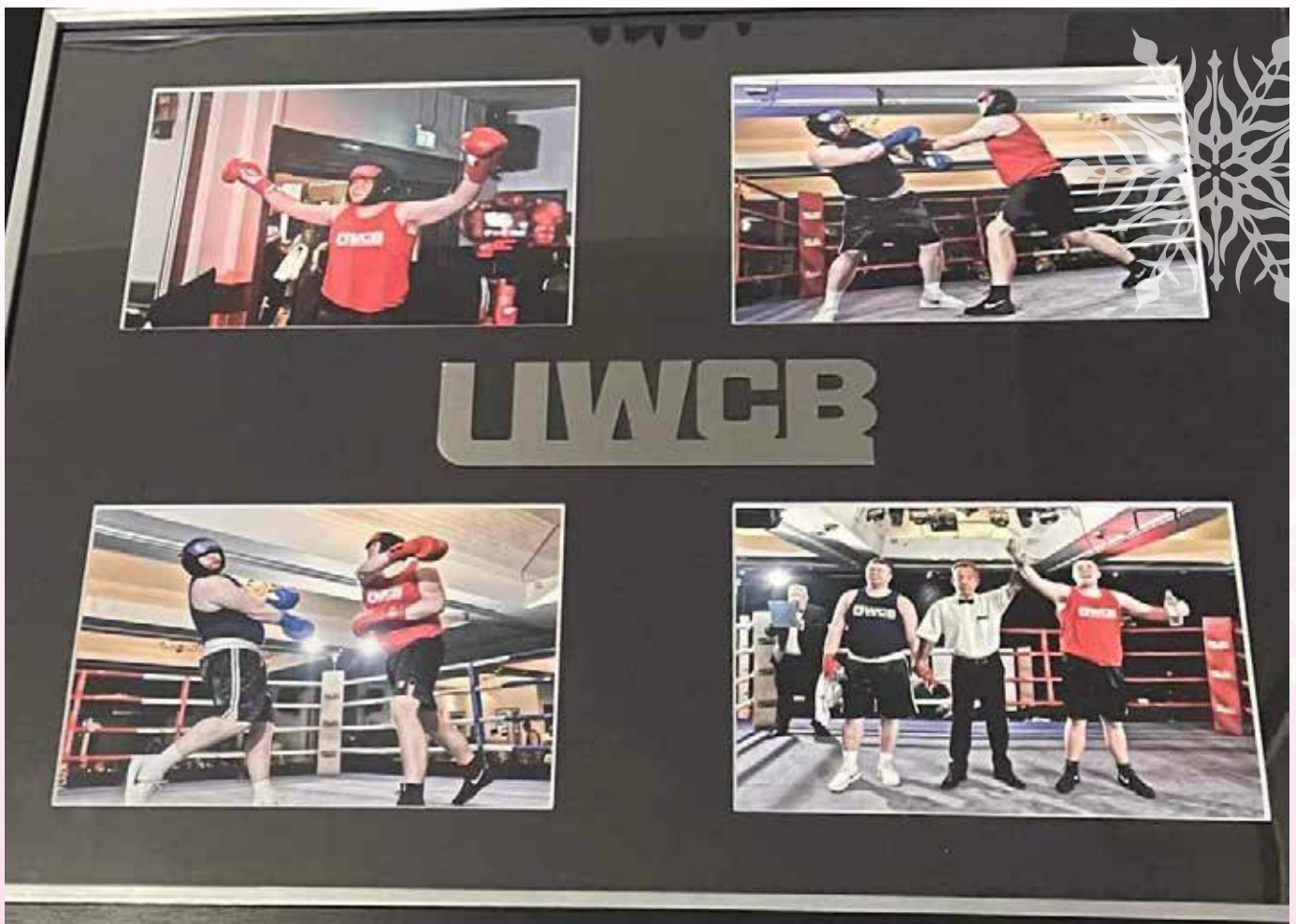
Boxing clever!



Ewan Kelman

recently took part in a charity boxing match and raised about £1000 for CDH UK. He also managed to win! His inspiration is his little Sister who has CDH.

Well done Ewan and thank you!



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Our Fundraising CDHeroes!

A fundraising takeaway!



Me's cafe

has been amazing in supporting CDH UK in memory of Micah.

This year they have carried out more amazing fundraising and awareness and we are so grateful!

Keep up the great work and thank you



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Our Fundraising CDHeroes!

Cycle 4 CDH!

Drew and friends

completed the London to Brighton Bike ride 2023 for CDH UK despite the unrelenting heat and managed to raise an amazing total of **£2312.50** with gift aid. They did this because a friend had lost their baby to CDH and they wanted to support them and other families affected by CDH.

What a great accomplishment and thank you Drew, Sharon, Dominic and friend!



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A chat with Katie

Secretary & Committee Member

Katie Chapman is our CDH secretary and committee member. Our Volunteers are extremely important to us and we love to celebrate them during Volunteer week which takes place during the first week of June and coincides with CDH Awareness Month. We took some time out to find out more about Katie's role.....

Q What is your role?

Secretary and Committee Member

Q What made you apply?

9 years ago my son, Logan was born, and we discovered at 4hrs old that he had a congenital diaphragmatic hernia (CDH) With no information and looking for support, we found CDH UK. I joined the charity so I could help families as soon as they receive their diagnosis and to raise awareness.

Q How long have you been doing this?

I joined in May 2019. The time has gone so quickly but it's so rewarding to be able to help others in a situation I'm so familiar with.

Q What has been a highlight?

There have certainly been a few over the years. Firstly, I've been extremely fortunate to be able to attend and represent the charity at the International Conference each year. It's great to see the work taking place across the world, to understand more about CDH and the cause. Secondly, meeting our amazing families each year. It's lovely to see the families that we support each year and catch up to see how they are getting on.



Photographs in the feature depict images of Katie with her family; husband Chris and sons, Logan and Harley.

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A chat with Katie

Secretary & Committe Member

Q What new skills have you learned?

I've definitely learnt how to evolve between different situations in my role. At times I can be speaking to an expectant mother who has just received a CDH diagnosis to a parent who needs our help with funeral costs. I'm also learning all the time about the inner workings of a registered charity and what is required.

Q Talk us through what a day as Secretary looks like.....

Every day is different which keeps me on my toes! First thing in the morning I check my emails to see if anything urgent has come in over night which I need to deal with.

As I also have a full time job, I pop some time into my diary for any other tasks that day. I receive requests for support on receiving a CDH diagnosis so I then email the parents with some information including one of our support packs and links to our support groups. I then liaise with our volunteers to check stock and request for items to be sent out. In the evenings, I check my emails again and respond to anything that has come in during the afternoon. I also prepare for anything coming up such as meetings, events etc. It's a busy job!

Q Tell us a bit about you and your experience with CDH?

I live in Peterborough and work full time as a Marketing & Commercialisation Manager. I'm married to my wonderful husband Chris and we have 2 boys, Logan, 9 and Harley 5.

I love to read (there's not much time though these days!), go on holiday and I recently got into fitness to improve my health.

I was a first time mum back in 2014, expecting a little boy. When Logan was born, I just knew something wasn't quite right, which was when we got the devastating news that he had CDH. Our world was turned upside down and we were left with so many questions. Logan had his operation at 7 days old and after 2 weeks we were able to go home. It was such a scary and anxious time but I'm thankful that I found the charity and I can now help people just like I was supported 9 years ago.



Thanks Katie for giving us an insight into your role and for all that you do for CDH UK!

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Support feature

Helping families through difficult times

Christmas or other religious festivals and celebrations aren't always happy or welcome occasions for everyone and for some families it can be a really difficult time of year. Whether it is because they have received a CDH diagnosis, due to give birth, lost their child or have a child in hospital at this time of year, celebrating or feeling festive isn't always a priority or reality.

Bereaved families can dread the festive period as it gives rise to lots of emotions that can be difficult to deal with when the expectation all around is to be 'happy' and 'jolly' and for lots of social interaction. These expectations often create heightened anxiety and feelings of loss.

This time of year also comes with tasks that require focus and organisation, such as deadlines to finish at work and shopping lists to create and get through, family visits and meal planning etc. this can be difficult when emotions are heightened and there are appointments and hospitals in the mix. This is where family and friends can be invaluable by helping with organising things and events and by being understanding if things don't go to plan. Friends and colleagues should try to be understanding if you decide you want space and don't want to socialise or attend the works party.

If you know someone finding things difficult then don't be afraid to reach out and ask them what you can do to help. Even little things like offering to look after animals, or doing their shopping can be a great support. Providing meals or taking them for a meal or coffee and chat can take their minds temporarily from the stress and can help them to feel some normality. Don't be surprised though if they thank you and refuse your offer, sometimes just offering is enough to make them feel that people are thinking of them and there if needed.

Bereaved families often become disheartened when family and friends don't mention their child's name, so include it in cards and ask the family how they are doing once in a while and if they need anything. Doing a fundraiser in their child's name at times like Christmas can often be a great way to remember their child and to support other families too.

Language can be really important and it is always best to try to be neutral where possible. Sometimes families can for example lose their faith in religion, or dislike certain terms or references and so being neutral can avoid risking upset.

If you are expecting a baby, due to give birth or have a child in hospital, family and friends can be invaluable for helping out at home or bringing things to the hospital, providing lifts and keeping you up to date on the outside world! Try to make a list of things you might need and make sure you have people's contact details on your phone. If you know someone who falls into one of these categories let them know you are there for them and let them know how you can help. You literally can be a lifeline.

Whatever your situation just remember that there is always another Christmas or religious festival to celebrate so don't put too much pressure on yourself. Relationships can suffer during busy festive periods for everyone without the added stresses of grief, trauma or illness and so talk things through and make time for each other, giving loved ones space when needed. Most importantly don't feel alone. If you feel like you can't cope, then tell someone or contact CDH UK or other bereavement organisation. We can put you in touch with others going through similar and even arrange for counselling.

CDH UK is always here to help by email and through its forums, which are always open and our support line is available on 0800 731 6991 at the following reduced hours over the festive period:

Thursday 21st December – 08:30-17:30

Friday 22nd December – 08:30-17:30

Saturday 23rd December – CLOSED

Monday 25th December – CLOSED

Tuesday 26th December – CLOSED

Wednesday 27th December – 09:00-17:30

Thursday 28th December – 09:00-17:30

Friday 29th December – 09:00-17:30

Saturday 30th December – 09:00-14:00

Monday 1st January – CLOSED

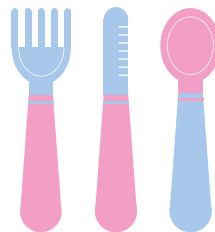
Tuesday 2nd January – Normal hours resume

COMING SOON from CDH UK

New for 2024
'CDH & Feeding'
booklet & a
'Patient Journey'
short film

We are excited to have created a new information booklet during 2023 to be published in the New Year and is focused on feeding. This has been created using our information production strategy and involved our members, end users and medical professionals. We are also looking forward to publishing a short film based on the patient journey and based on our research publication that we have worked on during 2023.

CDH and feeding



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CDH community Conference

CDH UK held its first CDH Community Conference in June 2023 at Alton Tower's. The idea of the conference was to create more than just a get together, to make it accessible to families, medical professionals and any other stakeholders.

Primarily, the event is to offer peer support but to also allow families to learn about new research and to participate where possible too. It allows medical professionals to learn what is important to families and how to improve their caregiving.



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CDH community Conference

During our pilot event families were able to chat and take part in some research using iPads and heard updates from CDH UK. They were provided with children's entertainment with a surprise visit from Duggie! lunch was provided and then attendees were given passes into Alton Tower's theme park to enjoy a fun filled afternoon.



The feedback we received was great and we hope to organise these every two years to fall between the CDH medical conference organised by the CDH Study Group and the CDH Euro consortium that takes place every two years.

Hope to see you at the next one!



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Awareness 2023

This year during awareness month in June we saw families holding fundraising events up and down the UK and taking part in jog 4 June 4 CDH. We also had an amazing nationwide light up of Colours 4 CDH on 28th June for CDH awareness day. We would like to thank every who took part to raise awareness to the general public and we hope to announce our 2024 campaign in the New Year.

Here are just a few of this year's colours 4 CDH pictures



Colours 4 CDH

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Awareness 2023 Colours 4 CDH



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2023 Snowflake Appeal

Each year we run a festive snowflake appeal to help raise funds for research. This year our appeal offering is a festive CDH awareness pack comprising of:

- Santa hat
- 2 Christmas decorations
- Pack of Christmas cards
- Snowglobe

The donation amount is £12

You can obtain your pack through our website shop or our eBay shop.



Christmas Crossword

1 DOWN

2 ACROSS

3 ACROSS

4 ACROSS

5 DOWN

6 DOWN

7 ACROSS

8 ACROSS

9 DOWN

10 ACROSS

11 DOWN

12 DOWN

13 ACROSS

14 ACROSS

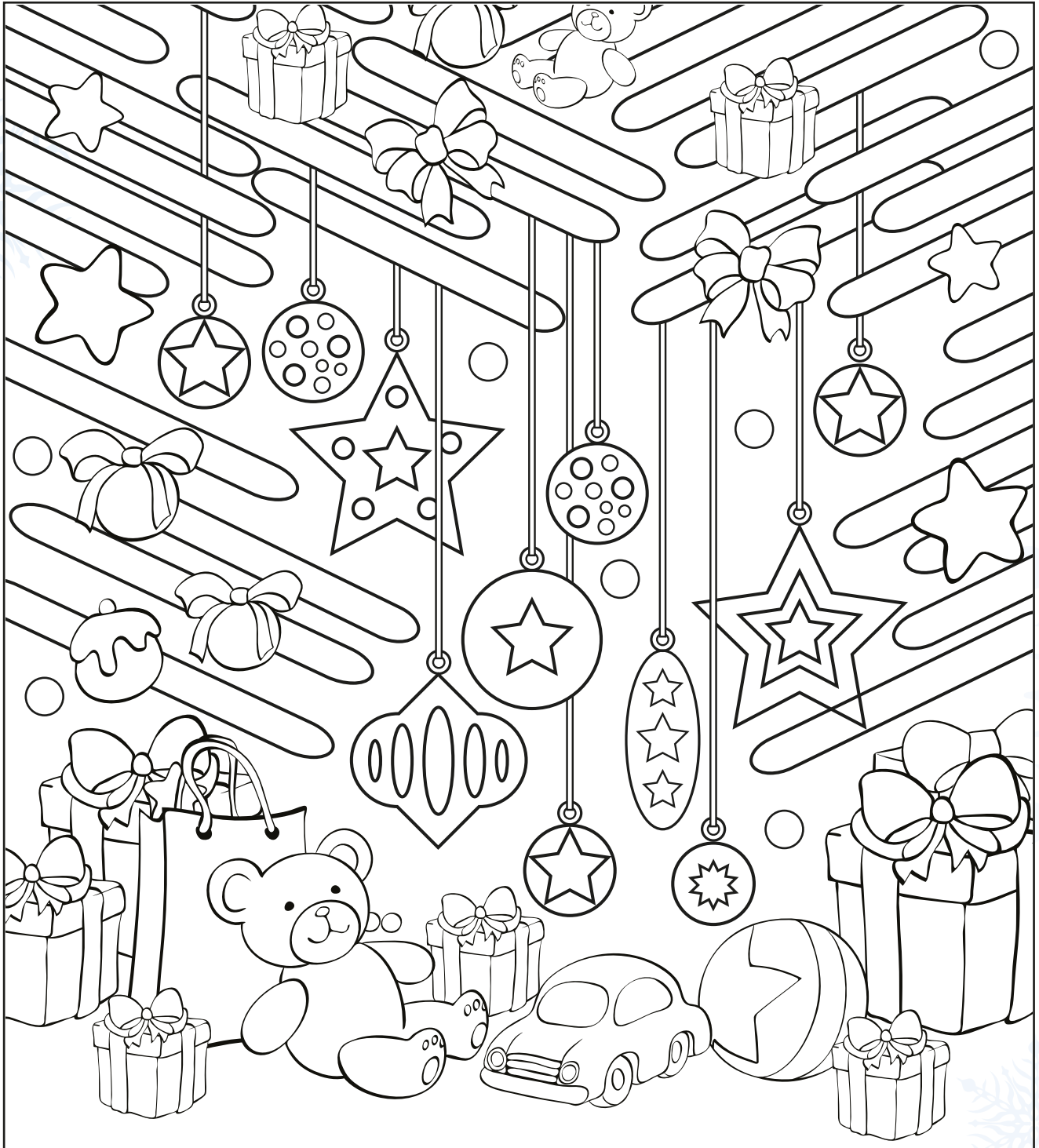
Rearrange the letters highlighted in pink in the crossword puzzle above to create a festive word below.

--	--	--	--	--	--	--	--	--	--

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Colour in the Christmas Tree, Presents & Baubles



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'White Christmas' song lyrics

Word Search

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

glisten
snow
hear
children
tops
white

listen
tops
tree
bells
christmas
sleigh

bright
dreaming
bright
merry



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

Enthuse
www.cd huk/enthuse.com/profile



twitter



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FACEBOOK



cdh UK

The Congenital
Diaphragmatic
Hernia Charity