



The CDH Magazine

Greetings from our Chairperson

Welcome to the very first edition of our new look newsletter renamed 'The CDH Magazine'! We hope that you enjoy reading it and find the patient stories not only inspiring but informative too.



After a very strange twelve months for us all, it felt good to be doing something in a familiar and relatively normal way; producing our annual newsletter, which is now renamed The CDH Magazine. Reading your stories reminded me that whilst covid-19 has brought new challenges in everyone's daily lives, CDH has been challenging families long before the other 'C' word ever existed, and that the past year has presented families with even more uncertainty and given us all a sense of having to accept and get used to our new lives. It really hits home that in terms of accepting a new life, this is something that our families experience when their child is diagnosed with CDH and that bereaved families live with every day. I am in awe of how our families have dealt with the added burden of Covid-19.

As a Charity we have done our best to support everyone through this crisis by liaising with healthcare professionals and carrying out our own survey to find out more about how Covid-19 has impacted on CDH patients and their families and by extending our support resources. We even took the opportunity to produce our own awareness face coverings! We have also had to learn to adapt our methods of working and to evaluate our priorities to ensure the smooth running of the charity during these difficult times. I think we have all learned some great lessons this year, not least to be kind to others and to give where we can.



Despite these challenges and changes we have had an extremely busy year working on more research projects and helping to develop other ideas and resources for our charity end users and I have been excited to see our Mobile app project move into Phase 3 of its development and to test a prototype (you can read more about this in the Magazine). I have also managed to attend further training courses to help me with my research and development role within the Charity. One of the highlights of 2020 for me was our Great Get Together and another was hearing that we are starting to see improvements in mortality due in part to collaborative efforts in research and better patient involvement in care choices and decisions. We still have a long way to go, because with improved survival comes a higher risk of ongoing medical issues and needs. Disparities still remain in low and middle income countries and our work with the Global Paed-surg project will hopefully help to reduce these disparities in the future.

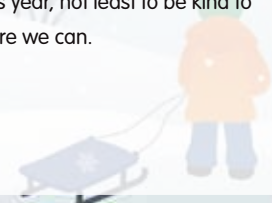
It has been a tough year for everyone in the Charity sector of course and not just for CDH UK. I can't emphasise enough how important your support has been during this 'annus horribilis' (a Latin term I will never forget!). Fortunately, due to having such a great team and some amazing supporters behind the Charity, we have managed to continue to operate with minimum disruption so far. I hope that you can continue to support CDH UK in 2021.

I would like to thank our hard-working Committee members and Patrons, who have continued to commit their spare time to ensuring the day-to-day operation of the charity during difficult circumstances, also each and every one of you who have supported our work.

A huge thank you to all contributors of our Magazine, without you we don't have a Magazine!

Wishing you all a very Happy, Healthy and peaceful Christmas and New Year!

Be kind 2021!
Love Bev x



Covid-19 & CDH

The Year of the virus

We have all had a very challenging year and when we first heard about Covid-19 we probably didn't realise just how serious things would become and how much it would impact every aspect of our daily lives. However for our families, this year has been exceptionally challenging.

Due to the virus being new, information has been very slow to filter through to the Charity and has therefore made supporting families more difficult. We decided during the first lockdown to develop our own survey to try to find out more about the impact of Covid-19 on patients and families and to see where we could help improve things in terms of support and resources and also to pass on any important information from the results to the medical community.

The survey was answered by over 200 participants and the full results can be found on our website. Thank you to all participants. We are hoping to carry out a shorter follow up survey very soon.

Here are some of the main findings in visual form



How many patient affected?

32 suspected cases living in a CDH household

10 with CDH



254 families participated so far



31.5% of patients received a shielding letter

10% Felt the letter received wasn't clear

93.42% who received a letter followed shielding advice



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CDH Research HUB

We have had a busy year with research this year and in addition to funding an important prenatal counselling study, we have also joined the steering group for the development of a Core Outcome Set for CDH (also known as a COS). These core outcomes sets act as a collection of outcomes and instruments that allows researchers to measure a consistent set of clinical endpoints in studies of CDH. Core outcome sets are developed through an evidence-based and set process during which all possible outcomes for CDH are methodologically gathered and then selected by an international group of experts and patients. We will keep you up to date on how this COS development progresses.

You can keep up with all research news by visiting our [website www.cdruk.org.uk](http://www.cdruk.org.uk)

Houston.....we have a problem called CDH and we are all trying to resolve it!

In February 2020, just before the first Covid-19 lockdown, the International CDH study Group and the CDH Euro Consortium held their CDH 2020 conference in Houston, Texas. The event was attended by specialists from all over the world including CDH UK who presented a published paper on Feeding issues and CDH.

We heard many interesting presentations on new and existing research. We were also very pleased to see more families and patient organisations taking part again and to meet them in person.

As with any medical conference there are many abstracts and new research projects to get excited about and Houston was no different and so we have picked out the ones that we feel are important and will hopefully make a difference both in the short and long term for patients.

CDH 2020 takeaways

- Exercise is good for CDH children and monitoring tolerance and providing counselling on lifestyle factors that helps to improve exercise capacity over time should be part of routine care.
- More evidence pointing to follow up care being key.
- One study showed that CDH children have more hospital admissions and higher rates of hearing loss, but no difference in educational outcomes.
- Cord clamping integrated into resuscitation/stabilisation of infants has the potential to improve outcomes.



Main Results

- Nearly 80% of patients experienced a feeding issue and only half have received a formal diagnosis of cause.
- Top three issues were Reflux (91.5%), Failure to thrive (62.2%) and Functional issues (83%) associated with neurological development.
- Feeding issues were described as picky eating (43.5%), Disinterested in food at mealtimes (31.1%), orally aversive (28.3%), Vomiting following food (25.5), Food aversive (23.6).
- Failure to thrive in 62.3%.
- Over half had clinical feeding support (nasogastric tube or gastrostomy). However only 30.2% attended a 'CDH Clinic'. 18.9% appeared to have no follow up.
- Hospitalisation following birth was over 12 weeks in 34.9% of patients with 23.6% receiving ECMO Therapy.
- Support and information was scarce with only 5% receiving counselling and 17% receiving information. Half of parents would have appreciated knowing antenatally of potential issues.
- Only 36.4% claim to have seen an improvement with school and social interaction.

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Awareness Month

This year we had to think outside the box a little bit in terms of our activities for CDH Awareness month, but to be honest lockdown helped us a bit because we knew that people wanted to try and keep busy and get out and enjoy some fresh air and so we partnered with an online digital platform to create our Jaunt 4 June virtual walking challenge that started on the 1st June. The challenge took participants on a jaunt around the UK, Ireland, Leuven and Rotterdam stopping at CDH specialist hospitals and research facilities along the way and then at one of the Royal estates in Norfolk before finishing at the hometown of CDH UK in King's Lynn. This was a total of 2500 miles (approx how many babies in 10,000 are affected by CDH).

We were very touched when a team of family and friends joined the challenge after Covid-19 meant they had to cancel a planned walk that they had arranged in memory of five year old Esma, who very sadly died from an undiagnosed CDH in May 2019. Our love and thoughts will always remain with The Guzels and we thank the family and friends who helped to raise an amazing amount of money in Esma's memory, which totalled over £2000 including Gift aid.



We also organised a Tik Tok challenge called [#KeepUpKeepOn4CDH](#) where you chose between football and Tennis and then had to see how many ball keep ups you could do before passing the challenge on to someone else. We had a few laughs watching the Tik Tok videos which we hope raised some awareness during June.

Thank you to everyone who supported our families and work by raising awareness in June.....same time next year!



Suz Lily

We're raising £100 to Help raise £100 to support the CDH charity in memory of Esma, a much loved and heart breakingly missed little girl...

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The Great Get Together

Each June CDH UK helps to raise awareness of CDH by encouraging people to take part in events and initiatives. 2020 was no different despite a national lockdown being in place. We had hoped to organise a family weekend event in person, but this obviously wasn't possible and so we changed our plans and organised an online event instead! Our virtual Great Get Together.

After months of preparation we brought together patients, families, healthcare professionals and medical experts in the field of CDH for a full day of presentations and break out sessions on CDH Awareness Day on 28th June. The event aimed to inform, update and educate on CDH research and relative topics to CDH and to engage patients and students in our work. Talks ranged from how the charity started to counselling and what to expect in the NICU and included lots of research presentations from some of the best CDH experts in the world.



'VIRTUAL' GREAT GET TOGETHER 28th June 2020



Session 1 - CDH UK

<p>Welcome to the journey</p> <p>Welcome & introduction from our Chairperson Beverly Power</p>	<p>Fundraising</p> <p>Kerrie Laird - Treasurer Everything you need to know about fundraising for CDH UK</p>	<p>Q & As</p> <p>Over to our attendees for Questions!</p>		
<p>10:00AM</p>	<p>10:10AM</p>	<p>10:20AM</p>	<p>10:30AM</p>	<p>10:40AM</p>
<p>Meet our Founder</p> <p>Brenda Lane - Founder In the beginning</p>		<p>Volunteering</p> <p>Katie Chapman - Secretary Getting involved</p>		

Session 2 - Prenatal & Perinatal

<p>Guest Speaker</p> <p>Neeltje Crombag - Midwife & Researcher, Belgium & UK Prenatal counselling</p>		<p>Guest Speaker</p> <p>Fiona Metcalfe - Lead Nurse - LGI Neonatal coping Strategies</p>			
<p>10:50AM</p>	<p>11:00AM</p>	<p>11:10</p>	<p>11:20AM</p>	<p>11:35AM</p>	<p>11:50</p>
<p>Prenatal diagnosis & Treatment</p> <p>Beverly Power - Research & Development Officer, CDH UK</p>		<p>Q & A's</p> <p>Over to our Attendees for Questions!</p>		<p>Guest Speaker</p> <p>Sandie Allison - Counsellor Bereavement & PTSD</p>	

Session 3 - International work

<p>Keynote Speaker</p> <p>Professor Dick Tibboel - Netherlands</p>		<p>Guest Speakers</p> <p>Frank Meijer - Patient Organisation, Netherlands</p>		<p>Q & As</p> <p>Over to our attendees for Questions!</p>	
<p>12:00PM</p>	<p>12:20PM</p>	<p>12:30PM</p>	<p>12:40PM</p>	<p>12:50PM</p>	
<p>Guest Speakers</p> <p>Olivia Spivack - ERNICA Project Manager How we are improving healthcare across Europe</p>		<p>IDEA Alliance</p> <p>Beverly Power - Research & Development Concept for collaboration</p>			
<p>Relax & Lunch</p> <p>1:00PM</p>			<p>Welcome back!</p> <p>1:30PM</p>		

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The Great Get Together

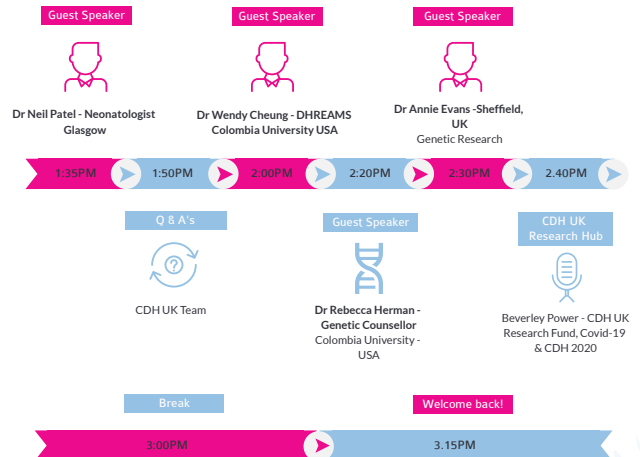
(continued)

We were really happy to also have the Dutch CDH group join us and tell us about their organisation and work. You can watch a recording of some of the presentations on the CDH UK youtube channel.

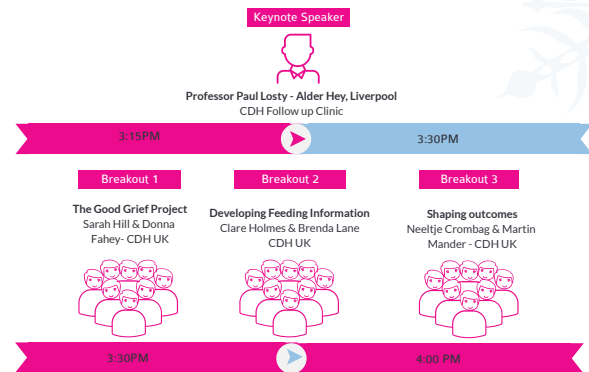
The event was a huge success and was well attended. We aim to host another similar event in the future.

Follow our social media channels to find out all about what events we have planned or coming up. Research information can be found on our Research Hub section of our website www.cdhuk.org.uk

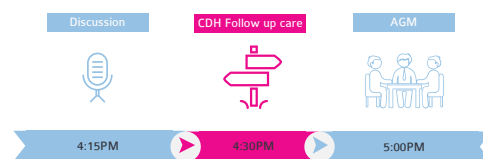
Session 4 - Research



Session 5 - Patient & Family



Closing Session followed by AGM



#JoinInJune4CDH

Thank you for your support!
For any questions or feedback please email committee@cdhuk.org.uk

SOURCE:
CDH UK June 2020

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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.



Carly's CDH story

My name is Carly and this year I turned 40 years old. I was born in October 1980 on my due date. Back in those days antenatal ultrasounds were not readily available and progress of pregnancy was monitored just by listening to the foetal heart rate and measuring fundal height. When I was born on 8th October 1980, I was just 6lb 3oz and was left with my mum after the birth. My understanding is that my birth was uncomplicated. However, I owe my mum to the fact that I am here today. I was her third baby and she automatically realised that my breathing was different to my elder brother and sister, and she alerted the midwives on the ward. Unfortunately she was told that she was an over-protective mother and that my breathing was of no concern. My mum is not medical, so although what she was told was against her instincts and better judgement, she trusted the midwives to recognise any unusual symptoms, so she took their word for it and remained on the postnatal ward with me overnight. The following day, the alarm was raised and it was clear I was labouring for breath (I imagine that my oxygen saturations were low) and I was blue-lighted to the local neonatal unit for further investigation. My poor mother was told that she would have to make her own way to the neonatal unit on the other side of the city. And without further consideration for my mum, they took me from her and left her distraught in the corridor of a busy maternity ward. She told me that she put up a fight to be transported to the neonatal unit and she was allowed to go with me in the end. Thankfully that wouldn't happen nowadays and mum would be encouraged to stay with her child.

At the neonatal unit I underwent some investigations, including a chest X-ray and that was when I was diagnosed with a congenital diaphragmatic hernia. My hernia was a left-sided (sometimes referred to as a Bochdalek) hernia, with a collapsed left lung; and both my intestines and part of my stomach had moved into my thorax. My prognosis was very poor (less than 5% survival) and my parents and older siblings were asked to say goodbye as there was little hope.



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Carly's CDH story (continued)

Even though my prognosis was extremely poor, I was lucky enough to be under an excellent neonatal surgeon – Miss Noblett, and I was rushed into emergency surgery just days old - I'm told that I was in surgery for something like 8 hours! I was also told that the procedure had not been attempted on many neonates and that it was videoed as a teaching source for other neonatal clinicians – although I'm not sure if that's true! I'm not sure how long I spent on the neonatal unit post-surgery (my mum can't remember exactly – it must have been a bit of a blur). When I was well enough, I went home to my family who lived just on the outskirts of Bristol.

I was a typical child, always trying to keep up with my older brother and was somewhat a tomboy – I enjoyed climbing trees and cycling for miles around the countryside north of Bristol. My childhood was normal and very fulfilling.

Now I have 2 children of my own (thankfully both very healthy) – Maya who is 8 and Arun who will be 5 in early December, and a wonderful husband. Back in the late 80's and early 90's I was denied a lot of treatment, including surgery to improve the extensive scarring across my abdomen. Back then I was hugely conscious of wearing a bikini when on holiday with my friends. Fortunately now I just accept the scar as part of who I am – the kids and husband are used to it and I would never wear a bikini now! I work as a pharmacist in a busy hospital. In the past, I supported the lead pharmacist on the neonatal ward – the same ward that I was a patient on back in the early 80's.

I would say that in my 40's I am the picture of health. Thankfully, I only suffer from reflux, asthma and breathlessness now. Sometimes I feel discomfort, but it has never stopped me achieving things in life.



I wanted to write, as I am not sure how many people who read this worry about their children growing up and living life to the full. I can say, as a CDH survivor, it is possible to have a fulfilling life. My passion is travelling and prior to the Covid-19 pandemic, we travelled far and wide. I am grateful to the team who looked after me and operated on me at Bristol Children's Hospital and especially to my mum, who recognised that I was so unwell – she saved my life.



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John's CDH story



John Foxall was born July 5th 2012 with CDH. His story has been told in a previous issue of this magazine.

In September 2019 he joined Beavers and he is incredibly pleased that within only a year and with a lot of hard work he has achieved his Chief Scout Bronze Award (along with an armful of other badges). He is pictured here receiving it in September at a socially distanced outdoor face to face meeting.

He is now a cub and has since September, been enjoying a mix of Zoom and face to face meetings, including hikes and tent building activities.

He is also very pleased that after even more hard work he is now able to ride a two wheeled bicycle without stabilisers.

We are very proud of John.

Richard and Dawn (Mum and Dad)



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Amelia's CDH story

Here is our brave Amelia's CDH story.

I hope it can bring some happiness to you all and some hope to those expecting.

Zoe Gill, Amelia's mother.



We found out that our baby had CDH at our 20 week scan (November 2019). Hearing that something wasn't quite right wasn't what we were expecting at all. Me and my partner 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.

So, I had the amniocentesis to see if our baby had any other abnormalities. This all came back clear. Big relief!

We then were referred to a hospital that deals with CDH which was Birmingham Women's Hospital. This was about 45mins - 1 hour drive away from our home.

This is where I then had to go to for all my appointments. I was seen about once a month by the Birmingham hospital and still kept my midwife appointments at home.

At Birmingham they did a scan and confirmed to us that the baby's stomach, spleen and part of its intestines had moved up into the chest area pushing the heart over slightly.

Next stage was to have an MRI scan to see how well our baby's lungs were developing. The results were that one lung seemed to be doing ok but the other one was small.

So, we kept having regular check ups at the hospital until I was 39 weeks. I was then booked in for an induction at 39 weeks (16th April).

The day before I went in to be induced on the 15th April, my partner lost his mum suddenly. It was heart breaking to lose her so close to our baby being born, so was so excited to meet our baby. Our emotions were all over the place having just lost my partners mum, excited to meet our baby and nervous/scared because we were in lockdown and so many things were different to how we wanted them to be for the birth.



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Amelia's CDH story (continued)

The next day I went in to be induced. We were in the middle of lockdown so my partner wasn't allowed in the hospital he had to drop me off at the door and he wasn't allowed to see me again until I was in the delivery room.

So 3 days past of me being induced and nothing really happening. So, they put me on the list to have my waters broken on the night of the 18th April. I finally got moved into the delivery suite so I could finally see my partner again which felt like it had been much longer than 3 days. Having to deal with all these emotions by yourself with no support was so hard! They broke my waters and put me on the drip. Contractions finally started and I was in labour for about 6 hours. 2am I was fully dilated and was able to start pushing. (19/04/20) 03.35am our beautiful daughter entered the world with a cry and was actually placed on my chest for a few minutes (I was so scared they actually did that, as I was told I wouldn't be able to hold my baby and that she would have to be incubated straight away). She was then intubated at 6 minutes old. I then said goodbye to her as they moved her to the intensive care unit.

My partner stayed with me for a little bit whilst I had to wait for a little surgery. As soon as I was out of that he had to leave (due to Covid). He was able to go and see Amelia for a little bit before he drove all the way back home for some sleep. (As we couldn't have accommodation at the hospital due to Covid). I then got moved onto a ward for recovery, which I wasn't allowed any visitors (due to Covid). I then went to visit Amelia later on that night.

Next day Amelia was doing so well they moved her to the Birmingham children's hospital (20/04/20). So later that night I got discharged from the women's so I could go and see her.

They explained that she was doing so well and they plan on doing the operation tomorrow (21/04/20). We was so shocked that they was doing it when she was only 2 days old.

So we head home that night to pack some more stuff and headed back to the hospital for early morning. Amelia went for her operation about 2pm and that afternoon was the longest afternoon of our lives. We finally had a call about 6pm saying she was back out and everything has gone well. We then got to see her again that night (only one at a time due to Covid).



The next day (22/04/20) when we arrived at her bedside we was told we were able to hold and cuddle Amelia for the first time. I couldn't stop crying with happiness. It had only been 3 days but it felt like a lifetime that we weren't able to hold her. It was amazing!

23/04/20 was my due date and Amelia achieved two big milestones. She was doing amazingly well that she had her oxygen tubes removed! We didn't expect things to move on so fast at all! Then later that night she moved from the intensive care unit onto a ward!

24/04/20 Amelia was able to have milk through a bottle for the first time! It was about 10ml and she drank it all!

Then every-day from then Amelia had to gain weight and pick up on drinking from a bottle, her weight would go up and then back down. She would manage so much milk but then she would fall asleep like it would tire her out too much. But slowly we got there, and after 3 weeks and 2 days in hospital our strong girl was able to come home. Still drinking some from the bottle and the rest we had to use her feeding tube for it. It was an amazing feeling to be able to take our little girl home.

Once home she lasted about just under two weeks and she decided to pull out her feeding tube. So, our community nurse said we will try her without and if she continues to put on weight, we will leave it out. That was it! It never went back in she has been growing nicely and feeding well ever since. She's not falling behind with her milestones either. She has done so well and we are very proud of her.



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Warwick's CDH story



Warwick was born in August 2002 four weeks early with an undiagnosed CDH. This was complicated by the fact they had to break his arm during the c-section. He had to be resuscitated and struggled to breathe on his own. They intubated him and investigations found his bowel was in his chest cavity. Later that day and they diagnosed CDH. They took him to John Radcliffe hospital and operated the next day with a repair. He was in PICU with 2 other CDH patients which the doctors said was really rare. His treatment was successful and he made great progress. He was transferred to our local hospital 2 weeks later and home a week after that. Fast forward 18 years. He is a sport loving Rugby player who has just gone away to University where he is studying Strength and Conditioning. He is playing Rugby for his County U20 team as well as his University Rugby team (when they are allowed to play again).

He struggled with asthma growing up and was medicated for it until his early teens which worried the doctors that it may restrict his growth. He is now 6 foot 3!

When he was born there was very little support available and a charity like this would have meant so much to me. I would have liked to hear about people like Warwick who had managed to live with having had CDH and still do everything that they wanted to do.



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Millie's CDH story



We just want to share how proud we are of Millie and how much she has achieved with her swimming.



Once we had confirmation from her surgeon that it was ok to introduce Millie to swimming at 8 months old she took to it like a duck to water. Even during lockdown when her lessons stopped she adapted and practiced in the sea instead!

Millie has just turned 4 years old and is able to swim a width of the pool completely unaided! All of that swimming has certainly strengthened her lungs and we feel has contributed immensely to her health improvements.

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'A Tale Of 4 Christmases'

That 1st Christmas was the second most painful day of my life. The first being 6 months earlier when our Teddy had passed away after a 17 day battle against RCDH in June 2017. Teddy was our first born child, so wanted, so precious and so longed for. That 1st Christmas, everything just felt wrong, full of 'should've beens', and we were completely consumed by the absence of him. It was agonising.

By the second Christmas, we had welcomed Teddy's little sister, Nina, into the world. Although our sadness of Teddy's passing was still there, she had brought pure joy to our lives and balanced the scales. We celebrated with all our family traditions, bought each other gifts from Teddy, and had his ashes (in a teddy bear) at the table for us to raise a toast to him at Christmas Dinner.

Last year, was the 3rd Christmas without him. We made decorations (including our "Teddy Star" for the top of the tree) to remember him, which Nina helped with, and again, set his place at our table and raised our glasses to him.

This year, will be our 4th Christmas, and we now have our newborn Matilda (Teddy's second little sister) to help us celebrate. Her and Nina both helped to put our "Teddy Star" at the top of the tree this year, something which will be an ongoing tradition in our family, to help our girls remember the brother they never got to meet.

Each year, it becomes more and more important for us to remember Teddy, and more and more important to include him in special days like Christmas. As our life has grown around our grief, it becomes easier and feels more natural to do just that, as we realise we never truly "lost" our son... He lives on in his beautiful little sisters, and in the hearts of all of us who love him.



Finley's CDH story



Our son Finley was born on the 5th of November 2018. I had a good pregnancy with Finley and everything looked to be healthy, there were no concerns in my pregnancy and nothing was seen in any of my 7 scans.

When my son was born on the 5th of November he was struggling to breathe and was very grey. He was taken down to the Neonatal unit straight away and placed on a ventilator. Within 3 hours of being born he was moved to Southampton Hospital to receive treatment in a Neonatal Intensive Care Unit.

My partner and I didn't know what was wrong and were told we could have a place at the Ronald McDonald House Charity to be by our son.

On his second day of life we were told he had a Right Sided Congenital Diaphragmatic Hernia. We were told that he needed an operation to save his life. We were shocked and had never heard of the condition before.

Finley had his op on the 3rd day and spent a following 4 weeks in the NICU. He op went well but he need a blood transfusion on his bowel and he also needed treatment for a lung infection. He had many ups and downs and there were points we didn't think he would be coming home. He came home on a couple of drugs to help with his hypertension and to help with reflux.

He's just turned 2 at the start of November and has just been discharged from his surgeon. There were points when I never thought this day would come and we forever grateful that he's with us today. Other than a scar on his tummy you would never known that he had been so unwell.

In June 2020 Finley became a big brother to a healthy little sister. During our pregnancy with Finley's sister we were so scared it would happen again, but she was born perfectly healthy and I think that may give hope to others looking to try again.



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Gracie's CDH story



Gracie Sayer was born on the 2nd dec 2015 at Southampton hospital. She had a condition called CDH. The left side of her Diaphragm had a large hole in it and unfortunately her bowel and other parts moved up into her lung and heart area, so this reduced the space for them to grow.

Gracie entered the world at 11.25pm. She was taken so quickly from me after birth. All I remember is being told I have to wait to see her. It felt like hours and hours until a Doctor walked in and said she's alive and stable. I followed this doctor so I could finally meet my first Daughter. As I walked in the room (with other babies in too), a lady in blue said "here's Gracie", she was so small at 5lb 5oz. She looked like she was asleep, she didnt move or cry. She was on a ventilator, there were so many tubes and wires. I was so overwhelmed.

I needed to make sure my Son Archie (who was 3 at the time) was okay as many hours had passed. They said things wouldn't change yet and so I went for a bath and the next thing I know my phone is ringing and a Doctor said Gracie has deteriorated too much and we need a plan B. I rushed back to the hospital and as I arrived with my family I was told she was dying and had less then 20% chance to live. She needed a machine called ECMO and this could possibly help. The Doctor started phoning other hospitals for their help, but unfortunately they were too busy with patients, but as time went on and we didnt have much time left, Glasgow's children's hospital said they could take her. It really was a life or death situation at this point.

As time went on she had ECMO and it made her stronger she had her repair surgery. This amazing team saved my daughter's life.

As the months went on, Gracie came back down to Sussex where our family lived and she went to Southampton again to the Queen Anne hospital in Portsmouth and then from there to St Richard's in Chichester. This little girl proved to the most experienced Doctors that she wouldn't give up. She just needed the right care and love.

Gracie was 8 months old when she came home for day visits and was allowed visitors to see her. She had her own room in hospital and we checked in a couple nights a week to stay with her. Unfortunately Archie was too young to understand all off this. It really was hard but we had a great family unit and the support of snowdrop trust to allow her to come home.

Gracie was 8 months old when she came home for day visits and was allowed visitors to see her. She had her own room in hospital and we checked in a couple nights a week to stay with her. Unfortunately Archie was too young to understand all off this.

It really was hard but we had a great family unit and the support of Snowdrop Trust to allow her to come home.

In June 2016 Gracie was allowed home full time with a house full of medications and feeding machines and also an oxygen machine.



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Gracie's CDH story (continued)



We had days out, she went to a park, a beach and had ice cream and we had sand sea and most of all she had Archie who loved her so much.

Me and my Mum sue shared shifts with Gracie, as she required 24/7 care. She always needed someone awake. I am very grateful for Mum's help.

Unfortunately on 1st July 2016 Gracie's oxygen saturation was too low and she was very blue. She couldn't breathe and so we phoned an ambulance and went back to hospital. This is where life turned upside down for us all.

Gracie's lungs were not growing with her body. Her heart and lungs had too much pressure on them and so off we go to Southampton hospital again.

They tried for 2 months to make her better again, but she couldn't fight anymore she had fought so much and The Doctors knew. Her fingers were turning blue and her tiny little toes. We were now having to make the hardest decision ever and turn off all machines and let her be free from this world.

On the 26th August 2016 our family came up to say goodbye to our little CDH fighter at just 8 months old.

I can now say she will be 5 this December and I can finally talk about her and the pain we all went through.



I would like to thank CDH UK, The snowdrop trust and Southampton PICU, Queen Anne's and St Richards and most of all our friends and family who were always there for us.



I share these photos and our story because when I was pregnant I didn't understand CDH and I didn't know what to expect and this is what happened; this is mine and Gracie's story.

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Penny's CDH story



Penny Nicole Livie was born on 11th January 2010 at 8.03am. I had a complicated pregnancy, bleeding from 12-20 weeks and a long labour, lasting a week, going in and out of labour. This started at 37 weeks so unfortunately not a lot could be done to push things alone. I had planned to have Penny, our second baby at the JR in Oxford.

Penny was born at Milton Keynes hospital in the end as it had been snowing heavily and we couldn't make the trip over to Oxford from Milton Keynes. It was an amazing moment seeing her little face and mop of black hair after such an ordeal and emergency forcep delivery. She didn't have a very loud cry and seemed to be struggling. Her body looked slightly lop sided but the doctors and midwives assured us that all would be okay and she would be better after a feed. I tried to breast feed with no luck. Unfortunately I became poorly so was whisked away to surgery. My husband was left with Penny and felt very sure something was very wrong.

I couldn't wait to hold Penny when I returned from surgery around 3PM. She was dressed and had her eyes open. She just gazed at me, very still and quiet. Trying to cry once in a while. I continued to try and feed with no luck. I became very weak with a temperature and at around 11pm the nurses became concerned and took Penny away to be checked over and give me a rest. I felt like I was on death's doors but couldn't sleep until I knew what was wrong. Initially a chest infection was suspected.

The most terrifying news came at 3pm when a doctor visited me without Penny saying they thought she was very poorly and had put her onto a breathing machine. Tests were being performed to find out what was wrong. I layed in bed feeling utterly hopeless and terrified.

My husband anxiously arrived first thing in the morning. We went to see Penny, she had been put in the intensive care baby unit. she was fast asleep and there were tubes everywhere! It was beyond frightening and we were devastated. We were allowed to hold her hand. We just sat waiting and watching.

After further tests and procedures, we were given the news that Penny had right hand sided CDH. We were told she was very poorly and would need to be transferred to Oxford for an operation. The days that followed were a blur, we desperately waited for Penny to be strong enough for the operation. On day seven the operation took place. We had been offered a baptism the day before which we declined. We were adamant she would be christened with her brother. Looking back I'm not quite sure why we decided this when we knew what we could have been facing. After all the scenarios we signed the paperwork and allowed the doctors to take Penny to the theatre. It was horrendous and still ten years on the thought brings tears to our eyes. My husband then saw me off to theatre as I had been re-admitted due to further complications. It was a nightmare.

Hours later when I had recovered, my husband wheeled me over to see our baby as we had given the news she was recovering well enough for us to see her. It was the happiest moment, we were relieved to see her and find out the good news that all had gone so well. The surgeons had put her intestine and heart back in the right place and sewn up the hole in her diaphragm. Luckily in Penny's case her liver blocked the hole stopping all of her intestines travelling up into her chest cavity. Still on a breathing machine and lots of medicine, we waited anxiously to see if her second lung would inflate. I had managed to express a small amount of milk which was fed to her through a feeding tube as her first feed. She still looked swollen from

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Penny's CDH story (continued)



the steroids and would be on pain relief for the days to follow. We were incredibly fortunate and after a week Penny could come off the ventilator and start to feed from a bottle. She had done better than ever expected. At 3.5 weeks we took Penny home to meet her brother Ethan and family. It had felt like a life time of worry and torture. Despite Penny still having a long way to go, we had been given a second chance. The hospital, doctors and nurses had all been amazing and we will forever be grateful for what they did for us. The months that followed were very difficult. Penny was still week and picked up bugs and we were in and out of the hospital for what felt like forever. I was also poorly with complications and had developed PND due to the separation and stress. We pulled through and eventually things got better and we became the very happy family we are today. Penny has not had any further problems and lives a perfectly normal, healthy life. She enjoys all sports and is especially good at gymnastics.

Life was tough for a while but we know how lucky we've been. Due to health problems we didn't think we could have another baby until pleasantly finding out I was pregnant in 2018. The pregnancy was high risk but all was well with baby number three.

Sending love and positivity to all CDH families.



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A chat with Chris... Our Fundraising CDHero!



CDH UK Interview Questions and Answers:

Q Tell us a bit about yourself Chris and what made you decide to set this challenge for yourself?

A I'm 36 years old, father of two beautiful daughters Poppy (7) & Jessie (5), and partner to their wonderful Mummy, Hannah. We live in Atherstone, Warwickshire, and have done since 2018, after moving from my home city Derby. I work for Jaguar Land Rover in Coventry, usually based at their Whitley site, but for the majority of this year, I've worked from home due to COVID-19. My partner and I have raised money for CDH UK previously, back in 2014, we held a charity ball arranged by us and a group of friends. The event was a huge success, but I've always felt I would love to do something personally, some sort of challenge, but wasn't sure what? Until a friend (Matt) joined my team at work in July 2019, Matt was in the middle of running a 5kms every day challenge throughout 2019. I'd never heard of a challenge like it and spent the next few months thinking about the challenge, and how it could be a great one for me to do. Not until the middle of December (2019), did I decide let's give it ago, it was a daunting decision for me, as I'd never been much of a runner, but I wanted to do something that would challenge me physically and mentally. For me, it reflects a small similarity to the daily life of living with CDH and having to manage the challenge around daily life; work, family time, and social events.

Q Tell us more about the challenge?

A The challenge is to run 5km's every day of the calendar year and in my case 366!! To run it when and where ever I can fit it in. My friend Matt, who completed it last year, gave me a great piece of advice "it's only 30 minutes, which equates to 1/48th of the day". As I write this, I've completed 337 runs, equating to 1800+kms (1100+miles), at 23 different locations, with over 300 of them in and around my town (Atherstone). My 5k time has improved over the year, starting at just over 30 minutes and getting down to 22 minutes 31 seconds in June. I hope to improve my 5k time within the last month of runs, fingers crossed the weather and my body can allow another couple of attempts.

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...our chat with Chris (continued)



Chris Davies

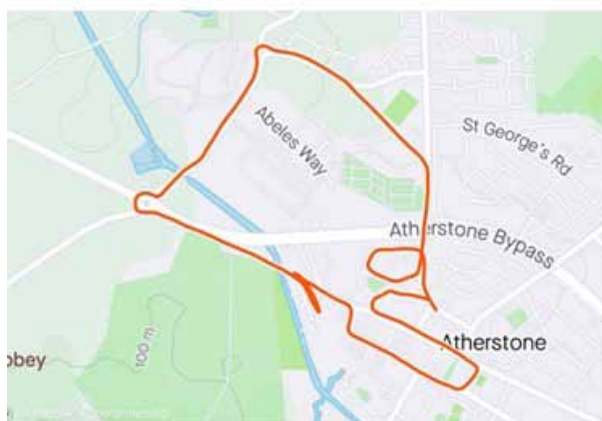
Yesterday at 11:00 PM

Day 176 of 366!! 23:00-23:59 done, twilight to darkness!! That's it 24 consecutive hours across 24 days!!

https://uk.virgi...

Read more...

Distance 5.09 km Pace 5:28 /km Time 27m 50s Achievements 1



Q Why did you choose running?

A As I wasn't much of a runner before this year, plus I wanted a daily exercise which would help get me fit and lose weight, to which I've lost over 7kgs (just over a stone).

Q What support have you had with the challenge and who has been your biggest supporter?

A Where do I start, the support I've received has been amazing, far beyond what I could've expected. I've met many families who have been affected by CDH, so many heartwarming messages, and donations along the way. Many of my friends have tagged along on several runs, it is great to catch up with them but also share the experience. My biggest supporter apart from my amazing family (Hannah, Poppy & Jessie) is Claire Dean, she has sent donations & messages every month, so generous of her. Claire is Mamma to a CDH Hero Evelyn. It continually overwhelms me the level of support I've received and has helped get me out of the days where my body is not too happy about going out. Thank you to all who've sent messages and donations, your generosity has really blown me away.

Q What has been the highlight so far?

A I've had several highlights, but the ones that stand out are the families who let me put the names of their children who've been affected by CDH on the back of a special t-shirt for me to wear every day, 18 names in total inc Poppy's. Every time I put the t-shirt on I feel empowered to get out there. Another highlight is incorporating as many special runs whether it's dressing up to mark Easter, VE Day, Halloween & Armistice Day. I also decided for my June runs, to run in every hour of the day spread across the first 24 days in June, Starting at midnight on the 1st June, finishing at 23:30 on the 24th June. Also ran at a number of locations, Mallory Park race circuit, Coventry Airport runway, Bruntingthorpe airfield, MIRA test track, and around my local football teams (Atherstone Town Football Club) ground. I've approached many different venues but Covid-19 has significantly limited them, but that won't deter me in my final month, as I still have a few planned.

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...our chat with Chris (continued)



Chris Davies

Today at 7:46 PM

**Day 183 of 366!! ½ way!! Same route as Day 1!!
01/Jan Day 1: 5.45km, 32:16. 01/Jul Day 183:
5.44km, 29:07 Wow, those 183 days have gone
surprisingly fast!! Thank you to all who've sent...**

Read more...

Distance	Pace	Time	Achievements
5.44 km	5:21 /km	29m 7s	1



Congratulations, this activity completed the July 5K!



Q What has been most difficult about the challenge?

A A couple of things have been challenging, keeping my body as fit as possible, getting on top of any niggle as soon as possible, I stretch a couple of times a day to reduce my muscles from stiffing up. During Poppy's 5 night stay in hospital in August, whilst having her tummy repaired, I was in and out of the hospital, also looking after her sister Jessie. A few of the runs I did late at night running around my garden, which isn't very big, equating 555 laps, taking 35-40 minutes. There's be several runs around the garden, the most recent due to having to isolate whilst waiting for Poppy's COVID-19 test to come back.

Q What will you do when it's over?

A Have a few day's rest, but I'll keep running a few times a week. Running every day has helped me so much mentally, especially during the lockdowns. I will miss the challenge, as it's one of the greatest things I've done, and will cherish it forever.

Q What do your family think about you doing this?

A Hannah: "I am super proud of Chris's achievement and determination. He has not once complained and has stayed positive all year. It's been a huge challenge for him and will be a great reminder to our girls that you can do anything you put your mind to as they get older."

Q How much do you hope to raise?

Initially, my target was £1000, but I achieved that at the beginning of May. Then I increase it to £1500 and again hit that at the end of August, so I increased it again to £2000. As of today, I've raised £1940, which is way beyond what I expected, but looking at how close I am with less than a month to, I would love to smash past £2,000 and hit £2,500!!

Q Why did you choose CDH UK?

A Ever since CDH UK began supporting my family back in 2013, the year of Poppy's birth, we've had an immense amount of gratitude towards the charity. For us their support was invaluable, giving access to other families who have been affected by CDH, financial support; paying for hospital parking fees, and giving us a grant, so we could purchase a travel system big enough to carry all of the equipment (ventilator, oxygen, suction unit, etc) to support Poppy on trips out.

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...our chat with Chris (continued)

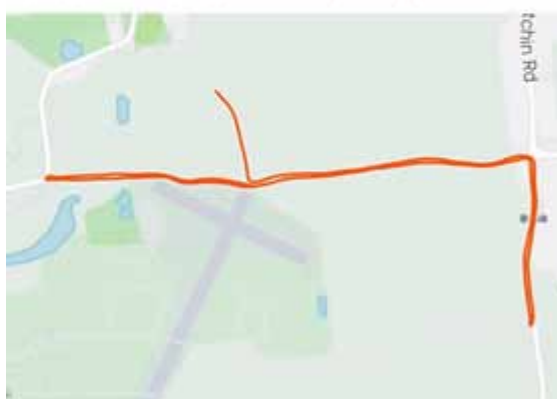


Chris Davies

Today at 5:39 PM

Day 200 of 366!! Two hundredth!! 🥳 Special one!! https://uk.virginmoneygiving.com/CD_5k_4_CDHUK

Distance	Pace	Time
5.65 km	5:13 /km	29m 28s



Q How is Poppy doing now?

A Poppy is doing fantastically well, she was 7 in October and is thriving at school. Although she did have major surgery in August of this year to repair her hernia, she soon bounced back from that.

She is a confident little girl with a lot of sass, who makes everyone laugh. She loves dancing and singing and is a big Little Mix fan!

Hannah and I couldn't be more proud of how she is, what she has overcome in life already is unbelievable and there's never a day that goes by where I don't think how lucky I am to be her Daddy.

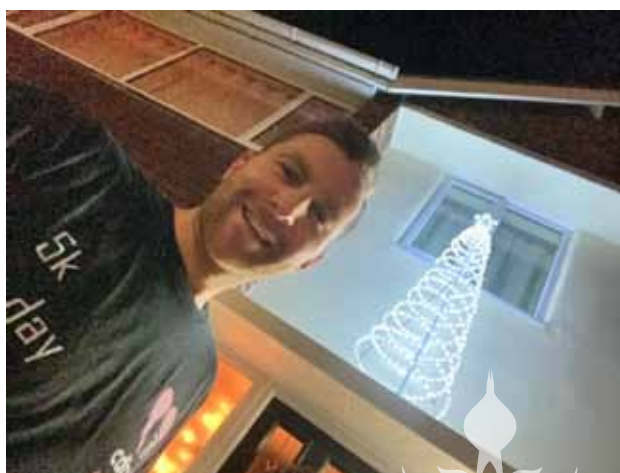
Q Do you have any tips or advice for anyone thinking of doing a similar challenge?

A Don't do it..... Only kidding!!

A few pieces of advice,

1. Only think about your next run, take it a day at a time.
2. Take it easy only go as fast as your body wants to go.
3. Enjoy it!!!

Our Charity work simply could not exist without your support and fundraising because we do not receive any funding from anywhere other than our voluntary income. Every single penny raised is so important, so whether you have raised £5 or £5,000 you are a CDHero on our eyes!



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25 years of supporting CDH families in the UK

25 Together 4 CDH!

This year we should have been celebrating 25 years of CDH support in the UK, as it was in 1995 (a year after the birth of their daughter with CDH) that Brenda and Kevin Lane began reaching out to families to help support each other. In 2004 after organising a few Get Togethers and raising funds locally, they were able to set up the first registered CDH Charity in the UK. Unfortunately our grand plans to celebrate came crashing down a little due to the UK lockdown. Still, we didn't let this phase us and we soon jumped into action to organise 25 Together 4 CDH, a virtual walk comprising 25 participants who walked from Land End to John O'Groats also known as LEJOG.

Danielle who lost her Son Kobi to CDH was one of the Team of 25 and has supported the charity despite going through her own grief and we will always remember Kobi and his family.



Rhi Slate and her Dad Richard also took part in honour of Rhi's Daughter Maisie who was born with CDH.....Maisie joined in with her trike!



Danielle

We will be starting a new virtual walking challenge in January so please keep your eyes peeled for further details on our main Facebook page.

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25 years of supporting CDH families in the UK

Another of the 25 came in the form of a very special little 3 year old lady called Millie, accompanied by her Mum Louisa. Millie soon became the Charity's mascot for the challenge and was given the moniker 'Major Millie' making her CDH's answer to Major Tom Moore and winning the hearts of everyone who learned of her amazing achievement! She appeared in her local newspaper much to the delight of us all, helping to spread much needed awareness. She really went for it and entertained us all with her fancy dress and various accompaniments such as dolls and bikes! As you can see in the photos she really was happy with her medal. We really cannot thank Millie and all of the people who took part in this challenge helping to raise funds during June, you are all CDHeroes.



We also held a competition for a new Facebook profile picture to reflect 25 years of support and we received some amazing entries. They are all winners but we chose Garry Richardson's picture to use as a profile picture.

Thank you to all who took part.



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Welcoming our 2 new Charity Officers



KATIE

Hi, I'm Katie, secretary and committee member for CDH UK.

I have been volunteering for the charity for 18 months now and it's amazing to be able to support families who are going through what me and my family did 6 years ago.

My son, Logan, was born undiagnosed until birth with CDH. He was treated at Addenbrookes hospital in Cambridge and after undergoing an operation to repair his diaphragmatic hernia we were able to go home. He is now a normal, healthy, if not slightly crazy 6 year old, but that certainly doesn't take away any future worries we may still have.

By volunteering for CDH UK, I get to share my experience whilst supporting other patients and their families. It's also great to be involved in new research projects, medical conferences and fundraising activities to increase awareness and raise much needed funds so we can keep supporting the families that need us.

We are always looking for people to join us so get in touch now!

Happy Christmas and here's to an even better 2021!

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Hi, I am Sarah the new Treasurer for CDH UK.

I first heard of CDH in 2010 when my first daughter was born with the condition, sadly Chloe was only with us for 12 days.

Up until recently I was a practice manager in a private healthcare clinic but before this, I worked in hospitality for 9 years running businesses.

I now have two daughters who are 9 and 6, we remember Chloe by helping to raise awareness and funds for CDH UK, the girls love raising money for CDH UK as they share Chloe's story.



SARAH



Collaboration updates



Ernica

We continue to work with the European Reference Network for Inherited and Congenital Abdominal Anomalies (ERNICA) and we have been invited to participate in the transversal working group for pregnancy and family planning and also research, for other ERN's including ERNICA. This year we have been involved in research projects and we have helped to develop an animation explaining CDH, that should be released in early 2021. We were also delighted to have Olivia Spivack, one of the project Managers talk at our Great Get Together in June. Unfortunately the annual ERNICA meeting was postponed this year due to Covid-19.

Gift-Surg

We are into our 5th year of working on this amazing international project by UCL, King's College and KU Leuven collaborating with clinical partners GOSH, UCLH and UZ Leuven hospitals and charities such as CDH UK. We are delighted to have been involved this year in the development of their new website which was launched in December 2020.

Please take a look!

www.gift-surg.ac.uk

Global Paed-surg

We were very pleased to learn that the Global Paed-surg project research is in its final stages of submitting for publication and we applaud the team for an amazing effort. We have helped by attending meetings and reviewing the manuscript and we hope to continue to help where we can. We are very excited to see this work published and to see this research translated to bedside to help in low and middle income countries as well as high income countries.



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Snowflake Appeal & Balloon Race

This year's Snowflake appeal is well under way and you can either name a snowflake in the name of a loved one for a donation, or you can purchase a beautiful snow globe that will be on sale until the end of December. You can find them on eBay or on our Facebook page. All proceeds go to our Research Fund.

In addition, we launched our first virtual Balloon Race to raise further funds. The race started on the 16th December and finishes on Christmas Eve.

The prizes of a £150 Amazon voucher, Boots £50 voucher and a luxury fragrance hamper were donated by Aqueous Digital and Acupuncture that works.

Winners will be announced on Christmas Eve.



Colour in Santa delivering his presents

(with a little help from an unwanted helper!)



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CDH UK

Christmas Pudding ingredients' Word Search

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



ginger brandy flour
orange eggs nutmeg
breadcrumbs sugar apples
butter raisins almonds

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

Virgin Money Giving
www.virginmoneygiving.com



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Diaphragmatic
Hernia Charity

