cdh UK The Congenital Diaphragmatic Hernia Charity

Hello from the Editor


My eldest son Louis (Right sided CDH)

Hello and a warm welcome to the CDH UK newsletter.

This year sees the ten year anniversary of CDH UK becoming a charity. Nine years ago I had my eldest son Louis (RCDH) and I felt very lonely and helpless until I discovered Brenda at CDH UK, who was at the end of the phone any time of day for me. I will never forget that support and am one of the lucky ones as Louis is now a healthy boy who is achieving all his peers are. The charity has got stronger and stronger and now reaches more people than ever through fundraising and social media which is fantastic progress.

We hope that this Newsletter will reach those who may need support and someone who understands, to help them through their CDH journey. We have stories from very brave parents and Grandparents who have chosen to share their very personal experiences with us. CDH affects us all in different ways but by sharing our stories we can help each other try to understand our emotions and our future with the condition.

We also share ways in which we can help support those affected by CDH and see what people get up to in order to raise money and awareness. Thank you to each and every one of you.

I do hope you enjoy reading this and that you know you are not alone and together we can help each other.

Johanna Smith, Editor

Dear readers…

Hello and welcome to our 10th Anniversary Newsletter.

10 years ago, CDH UK registered as a national charity. Little did I know that I would still have the privilege to be here today honouring you all who have travelled the CDH journey

Over the years, you have all been an inspiration to move the charity forward and to mould it's services to help families throughout the UK, Scotland and Ireland.

With all your wonderful help and support, we are now in a position to offer additional schemes to help families in need and to also embark on meaningful research that one day might help to better the treatment options for CDH patients.

With your help, we can continue to grow this support for families of the future. We do hope that many of you will join us in 10 years to honour, 10 years to remember, 10 years to make progress. Let's make the next 10 years even better!

Brenda Lane, Chair

News

CDH UK becomes official charity for Enrique Iglesias UK Tour 2014!

We are very excited to learn that The official UK Fan Club for Enrique Iglesias has put CDH UK forward as the official charity for the Enrique Iglesias UK tour starting in November and even more excited to learn that his management team have agreed and made us their official charity for the UK tour!

It all started with one of our families, the Weaver's, whose son Matthew was born with CDH and has had to overcome many obstacles in his life.

We are keeping our fingers crossed that a video starring Matthew will be aired at the four tour venues.

We would also like to thank the UK fan club volunteers, who will be collecting at the venues and who have been promoting our TEXT Giving number CDHU25 to 70070 on the official UK Fan Club Facebook page. They have also been obtaining signed Enrique memorabilia to raise even more funds.

HUGE thanks to all involved and good luck with the tour Enrique, we hope you have a blast!

Clothes for Charity scheme

Don't throw away your old clothes! Donate them to CDH UK through our 'Clothes for Charity' scheme and help raise funds for our cause.

All you have to do is simply visit www.clothesforcharity.org.uk/charities/cdh-uk/ and request your free clothes bag today. They even arrange a collection at a time to suit you too! What could be easier!

Goodbye and Hello to Treasurers, old and new

CDH UK would like to announce its new Treasurer Kerrie Laird but it's not goodbye to our Donna! For the past 7 years Donna Fahey has been our much loved Treasurer and an extremely valuable member of the CDH UK Team. As with all of our Committee members, Donna has donated much of her spare time to helping others, in addition to teaching part time in a local secondary school.

This year Donna decided to go full time with her teaching role, which now means that she has not got the spare time to commit to such an important role as Treasurer and she has therefore handed the role of Treasurer to newcomer, Kerrie.

Donna will still remain as part of the CDH UK Team as a Trustee and standard committee member. We wish Donna well in her full time career and welcome Kerrie to the team!

'Hello everyone. My name is Kerrie and I am 36 years old and live in Wokingham with my husband Steve and our two children, Hamish who is 4 and Mollie who is almost 2. Mollie was born in February 2013 with an undiagnosed CDH and she was subsequently treated in the John Radford for a number of weeks where she had a repair carried out at three days old. So far we have been lucky, in that she is a relatively happy outgoing little girl with only one relapse, which required surgery back in November of last year.

I currently work for a well known telecommunications provider, helping customers to change the way that they work, through innovation and technology and in my spare time I enjoy spending time with the family, going for walks, to the park and swimming.

Naturally, CDH is close to my heart because of Mollie, so when the opportunity came up for taking on the treasurer role I jumped at the chance and very much look forward to being part of the team and supporting everyone in their amazing fund raising activities.'

We would like to wish Kerrie all the very best in her new volunteer role.

Attention free Anniversary Giveaway!

With Christmas fast approaching, we thought that we would get into the spirit of giving and decided that as this year is our 10th Anniversary, it would be fitting to give you all a free car sticker as a little thank you for your support and to help raise CDH awareness.

To claim your free sticker, Please email awareness@cdhuk.org.uk with your full name and postal address. Thank you for your support.

CDH Fundisc!

UK drivers no longer need to display a tax disc on their windscreen, so we are asking you to display the FREE CDH Fundisc instead!

This is a great opportunity to help CDH UK raise funds and awareness whilst on the move! We already sell our car stickers in our online shop and now you can download a FREE CDH Fundisc to help raise funds and awareness for our cause!

Go to our website, right Click on the image to save it to your desk top or phone and then simply print is off and display in your old tax disc holder. If it prints out the wrong size, please email awareness@cdhuk.org.uk for a pdf version.

Please do it today and help raise awareness for CDH UK whilst out and about, or simply cut out the above image from your Newsletter!

Challenging CDH: A CDH UK Education and Support Day

A major event for all of our families is taking place on Saturday 20th June 2015 at the Park Inn by Radisson, Manchester. This is the first event of its kind for CDH families and will be an opportunity to have your say on the future care of CDH babies from diagnosis through to birth and beyond. There will be lots of valuable information and opportunities on the day to speak with medical professionals and to voice your opinions and concerns and also to hear more about how CDH UK is making a difference to care pathways and how we are encouraging and promoting research. This will be a family friendly event with discounted room rates for those requiring accommodation at the hotel. We will be making more details available before Christmas along with an eventbrite page to book your places. Please regularly check out our pages on Facebook and Twitter for updates on what we get up to.

Events

The Annual CDH UK Charity Ball and Butterfly Picnic 2014

This year saw CDH UK celebrate 10 years as a registered UK charity with a 10th Anniversary weekend of fundraising and family fun comprising of an open information day, Ball and Butterfly Picnic.

Our annual Charity Ball was held on Saturday 28th June (also CDH Awareness Day) and was attended by families and businesses. We welcomed special guest speaker and CDH UK Patron Professor Paolo De Coppi of Great Ormond Street Hospital and The Institute Of Child Health and our new celebrity patron Michael Thomson who played the part of Nurse Maconie and CDH Dad in the hit BBC medical drama series Holby City.

We were entertained by Comedian Mike Pugh and Canadian Rock Band Cherry Suede. We were also privileged to have part of the event filmed for a documentary being produced by a US based film production company. The event was a huge success and one we will never forget and has so far raised over £5000 for our charity.

We held our Butterfly Picnic on the 29th June, which was very well attended and saw families come together at Coram's Fields Children's play area in Central London for an afternoon of fun activities and a special tree planting, undertaken by Brenda Lane (Chair), Beverley Power (Secretary) and Michael Thomson (Celebrity Patron).

This oak tree is affectionately known as our CDH UK Tree Of Hope and is a special tree for all of our families to visit. It is located over by the small animal farm towards the left corner of the play area. We hope that you will visit it when you are next in London.

We would like to thank all of you who supported this weekend, whether it was attending one of the events, donating an auction, raffle prize, time or services, helping with arrangements or helping to promote the event.

Here's to another successful 10 years of supporting families, medical professionals and research!

DISCLAIMER

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

CDH 'Aw-hair-ness' campaign goes down a storm

This year we decided to make June our CDH Awareness Month, with the main focus being on CDH Awareness Day on the 28th June. This year saw lots of you raising your hair to raise awareness of CDH with our aptly named 'Aw-hair-ness' campaign.

We had families, children, members of the public and Doctors and Nurses joining in too! We hope to see even more of you taking part next year, so watch this space for more news on what Awareness Day 2015 will bring during CDH Awareness Month.

CDH UK Get Togethers

We had Get Togethers in South Wales, Oxford and Glasgow this year and we enjoyed meeting faces old and new and having a great time. We were entertained by Creation Station and enjoyed family time. We would like to say a huge thank you to our Family Liaison Volunteer's Sarah Rollings, Megan Chapman and Monique Steel for hosting the Get Togethers. Here are a few pictures of what we have been up to.

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CDHeroes do it again!

We have had another terrific year of fundraising and many of you have supported us by organising fundraisers and events and lots of you joined in with our #1in2500 selfie campaign! It was great to see all of your wonderful and heart warming pictures flooding in.

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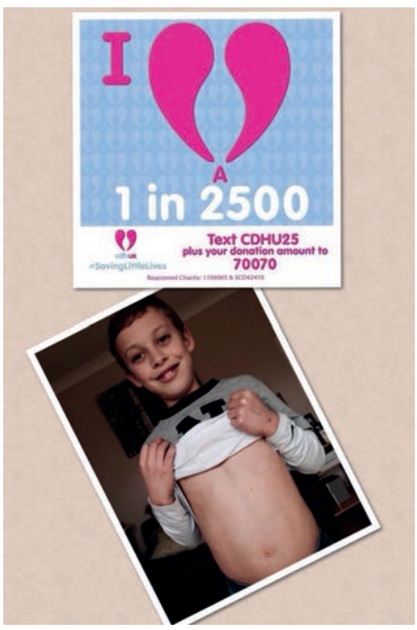

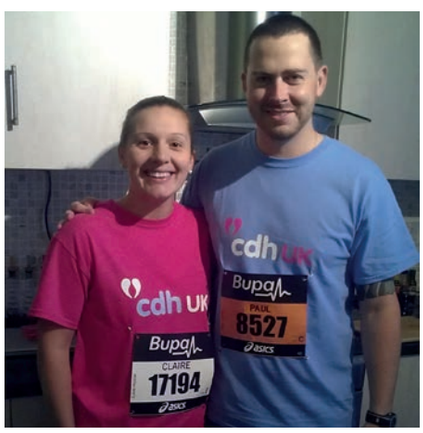

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Stories

Bethan Grace Lily Smith

We were over the moon when we found out we were expecting Beth. Our eldest daughter was conceived with IVF so when we fell pregnant naturally, we were overjoyed.

The pregnancy was going smoothly until our world came crashing down at the 20 week scan. We were initially told that Beth's heart was in the wrong place and had to wait for what seemed forever, for the consultant to see us and tell us she had a left sided CDH. She was given a 50% chance of survival. The following weekend was one of the worst in our lives, it was almost as if we had started grieving then.

For the rest of the pregnancy we were closely monitored, having regular ultrasound and two MRI scans. I also became quite poorly at the end of the pregnancy and was admitted to hospital for a week with gallstones. This was nothing compared to what Beth would face when she was born and I remember wishing I could keep her in my tummy forever and keep her safe.

She was born on the 30th October and although the birth was challenging, she was stable quite quickly and the hospital staff seemed optimistic. She was transferred to the Children's hospital and survived the repair operation. On Friday 8th November she was extubated and put on C-Pap. We had our first real cuddles and Matt helped the nurses give her a bath. We were told it was safe to buy her clothes now and her Nannie got some gorgeous outfits for her to wear. There was talk about moving her to HDU and the word 'home' was even mentioned. We went to bed that night having had the best day with her.

We were woken by a phone call at 6am the following morning. We ran to the ward where we were told that Beth had suddenly deteriorated. That morning at 7.20am, Beth passed away. Both her lungs had collapsed and we since found out that she had pneumonia.

Our world as we knew it ended that day.

We have however been humbled by the amount of support we have received from family, friends, work colleagues, the Chaplain who performed a blessing ceremony for Beth and her funeral but also people we have never met in person. CDH UK has been such a godsend for us. We have made friends with expectant parents, parents of surviving children and also parents like us. The support we have through the groups on Facebook has been endless. We will always be grateful for that.

We were lucky in that we got to meet Beth and she got to meet her grandparents and her uncle and one of her Aunts. So many little Angels don't have that. We hope that she knew how loved she was.

We have decided that we will fundraise in memory of Beth for the rest of our lives, it would be so fantastic if we saw a breakthrough in the treatment of CDH so that the chances of survival improve. We hope one day to meet her again and that she will be proud of us.

Carol Di Folco

My name is Carol and I am an undiagnosed right-sided CDH survivor. My parents were advised I had a 50% chance of survival. I spent 3 months in hospital and was then sent home with the Doctor basically saying there was nothing else they could do.

My parents did not know what to expect, as Doctors advised there might be developmental problems. I had issues with feeding and took forever to take a bottle but glad to say I developed quite well considering.

There have been various surgeries, a hernia repair and plastic surgery to improve body appearance, as there was a definite chest wall deformity. This was in my early teens and the outcome was not great. I have also

had two operations for adhesions of the bowel due to surgery when born, a breast augmentation to improve my chest shape due to lack of development and the chest wall deformity in 1992 and in 2012 had to have them removed and replaced, due to the breast implant rupturing.

This last year I have felt very tired, run down and suffered a lot of headaches in the morning and was struggling at my work to stay awake. This was not like me and I did not like feeling like this, so I started getting checks done at the Doctors, which lead to hospital referrals to chest a specialist and then a sleep clinic and in December I was given an APAP sleep support machine, due to oxygen levels dropping because of bad lung function and damage to diaphragm.

It has not been easy with my machine but I was not giving up on it as many do. Now that I have the correct size of head gear I am getting over 7 hours a night with my mask and glad to say I am feeling much better. I have 13 scars and a mishaped body but I am here today, reasonably health and proud to say I am turning 40 on the 21st June.

Cody Johnson

My Civil Partner Sharon and I have always wanted children ever since we got together in July 2008. We looked into and tried many different methods to have a family of our own. We thought and talked about adoption, we looked into co-parenting with another couple, we tried artificial insemination at home but none of them were working or sounded right for us.

So in October 2012 we went to the Gay lifestyle show and saw the ideal way for us to have children of our own was through becoming an egg donor and in return getting free IVF to have the family we always dreamed of. At the time I was 21 and Sharon was 41, so with Sharon being too old to be an egg donor, I willing became the egg donor and the one to carry our baby.

We picked our sperm donor from the clinic's own sperm bank as that way we didn't have to have it imported or screened for diseases. It was already done for us. We picked a donor that matched Sharon's Asian background so that the baby would be more like her as well as me.

We had to go through all sorts of test and procedures including a full physical examination (including a pelvic exam), a transvaginal ultrasound, to evaluate my fertility and the health of my ovaries, blood tests to test for a variety of diseases (including STDS and AIDS) and genetic testing. We even had to see a Counselor before I could be considered as an egg donor, mainly to see if I would be able cope with giving my eggs away and how would I feel if the recipient got pregnant with my eggs.

Once the clinic found a suitable recipient, treatment started. Both mine and the recipients menstrual cycles were regulated to match and I had to take hormone injections for about 10 days to stimulate my ovaries to produces a load of eggs. I had to be monitored every couple of days or so to check the development of the eggs. When the eggs were mature enough I had to have another injection so the egg collection could take place in a couple of days time. The egg collection took about half an hour or so to complete and I was under general anaesthetic, so was asleep through the whole procedure.

Afterwards I was a little sore and in pain but nothing that I could not handle. The eggs were divided equally between the recipient and I and the donor sperm we had chosen was added to the dish containing the eggs in the clinic's lab.

The clinic phoned me the next day to let me know the outcome of the fertilization and they then arranged for me to come back to the clinic in about 4 days time for the eggs to be transferred.

Sharon and I chose just to have one egg transplanted back because I was young and more likely to get pregnant first time. I was put to sleep again when they transplanted the egg into my uterus and when I woke up I was fine, I did not really feel any pain, just a little uncomfortable. I did a clear blue pregnancy test at home about 10 days later with Sharon by my side and I was pregnant.

After being disappointed so many times in the past, Sharon and I were delighted and so happy that we were finally expecting a baby of our own but our happiness was soon shattered when we went for my early pregnancy scan and they found nothing. We were devastated.

We talked with the fertility nurse about the scan and she gave us a few reasons why nothing was showing up on the scan which included miscarriage, eptopic pregnancy or the egg could have implanted later then they thought it had,. They advised me to have blood tests every two to three days so they could keep an eye on my HCG level and over the week the HCG levels continued to rise which was a good thing. At the end of the week they offered us another scan and we finally saw a little sac measuring 3.2mm. We were over the moon to finally see the start of our baby.

They stopped the blood tests and wanted to see us within a week or two so they could see the heartbeat. About two weeks later, we went for the faithful ultrasound that would tell us our baby had a heartbeat, I have never been so nervous in all my life. As Sharon and I sat there in the waiting room, waiting for the ultrasound, I started to panic and cry at the thought of them saying something bad had happened to our baby

When they called us in, I was in a pretty panicked state and as soon as she started to do the ultrasound she said "We have a baby and a heartbeat". To this day those words still echo through my head. We both started to cry with happiness that our baby was OK and that we could finally start looking forward to being parents.

As well as the usual 12 weeks and 20 week scan, Sharon and I paid to have two private scans done, one at 16 weeks, to find out the gender and a 4D one at 28 weeks. My pregnancy went smoothly and without a hitch until right at the end, when at 39 weeks, I went in for reduced movements and found out our baby had his bowels in his chest and had a condition known as Congenital Diaphragmatic Hernia or CDH for short.

The first thing I thought was that we would lose our baby, as I only ever heard of it on the television programme One Born Every Minute and sadly that baby did not make it.

The next day I was sent to Sheffield's Jessops Wing to be formally diagnosed that our baby had this often fatal condition. Over the next few days we did not even have time to really sit back and think about it. I was sent all over Sheffield for different scans and tests. Our baby was given a 60% chance of surviving. Normally these babies are only given a 50% chance of surviving but with our baby being diagnosed so late on in my pregnancy and with them believing it had happened after 28 weeks, the Doctors were more optimistic.

I was booked to have an induction 5 days after our baby was diagnosed with CDH, and I was very scared that we may lose the one thing in our lives that we had worked so hard for and excited at the same time at the thought of finally being able to meet our baby.

My waters broke in the early hours of Thursday morning after been induced the day before and I was taken to the delivery suite but no matter how hard the midwives and doctors tried, my body would not dilate and every time they turned up the induction drug our baby's heart trace would go bad.

After trying nearly all day, the Doctors decided it would be best for me to go down to the operating theatre and have an emergency caesarean. During this whole time, Sharon was right by my side.

After a very emotional and exciting day, our baby boy Cody was born at 17:05 on his due date by emergency caesarean on Thursday 7th November 2013.

I was warned that he may not cry when he was born because of his condition but he managed to let out a little cry. After he was born they took Cody straight away, and the midwife came out from the back room to tell us he was fine and that he weighed a healthy 8lb(3.62kg). Aftter they got him sedated and on the ventilator in the back room, Sharon was allowed to see him for a few minutes before they moved him over to NICU. I did not get to see Cody until the next morning, Sharon, and the nurses taking care of Cody, took some pictures of him for me to look at while I was recovering from my caesarean.

I had my own room on the postnatal ward as they thought it would not be nice for me to be in a bay of four beds with everyone else enjoying their babies while mine was in NICU. The midwives were so good to me and would ring NICU regularly to see how Cody was doing for me. As there was a sofa bed in my room Sharon was able to stay by my side and be close to Cody.

The next morning, Sharon took me in a wheel chair to see Cody for the first time. I was so happy that I was finally going to meet my little boy but nervous at the same time. When I first saw him I was so shocked to see him with all kinds of wires everywhere hooked up to different types of machines. I could not believe what was happening to my little man. He looked so helpless just laying there in his incubator. The nurses said it was OK for me to touch him but that he would not respond because he was sedated. I felt so guilty thinking it was all my fault that he had ended up with his terrible disease. The nurses and Doctors reassured me that it was nothing that I have done and that they do not know what causes CDH.

Sharon and I spent all most of the day by our boy's side. The Doctor told us Cody was doing well and that he was stable enough to have his repair and they went through again what would happen during the operation and that he might get worse before he gets better. They planned to do his operation on Sunday. The only problem was there was no bed over at Sheffield Children's hospital ICU, so we had to wait for a bed to become available before they could transfer him over for his operation.

That morning a little baby girl died suddenly from CDH over at Sheffield Children's hospital, I was so upset and shocked to hear this as she was doing ever so well, I did not tell Sharon about the little girl as I did not want her upset and worried.

While Sharon was at home and I was left alone at the hospital, it finally hit me, I remember just watching all the nurses and Doctors caring for Cody while I could do nothing for him but sit and watch him suffer. I burst into tears. I could not

believe what was happening. How could this happen? What did I do wrong? I had to walk out of the room, I could not stop crying and I was struggling to breathe. One of the nurses caring for Cody spotted me crying and she tried her best to make me feel calm and reassure me that Cody was doing well but I could not help but feel useless and hopeless. I was crying so much I could not even speak. In the end she called a midwife from upstairs to come down and take me back up to the postnatal ward. Whilst the midwife and nurse were trying to calm me down ,the Doctor turned up. He came to speak with Sharon and I about Cody's repair and give us an update on the situation over at Sheffield Children's hospital. With me being in such a state he said he would come back another time but I stopped him, as I just wanted Cody over at the Children's hospital to have his repair so he could start living a life.

I asked the midwife to stay by my side and sit with me in the family room while he spoke about Cody's repair, he told me Cody was ready since day one for his repair and that all his stats were steady and he was doing well and that he didn't want to waste any time and get him over to Sheffield Children's hospital for his operation. He told me a bed had become available over at Sheffield Children's hospital and that they were planning to move him over later that day, so they could operate on Sunday. He went through the operation again and went through the consent form with me telling me the best outcome as well as the worse, I signed the forms so that they was ready for when they operated on Cody.

Monday came and still no news on a bed at the children's hospital. Cody was doing well and was still stable and the doctors from the Sheffield children's hospital came to do their rounds. He talked with us and said that they were no beds that they know of that were becoming available anytime soon but told us things could change very quickly. He told us that they were thinking of doing the operation here at the Jessop's wing down in the operating theatre where they do the caesareans. Luckily that night a bed became available and transport was arranged to come and transfer Cody over to the children's hospital.
I saw him get taken away to the ambulance and as I saw him go out the double doors at the other side of the hospital my heart broke and Sharon and I began to cry. I was just hoping and praying that our little fighter would make it and beat CDH.

The next morning, I got a phone call just before noon from one of the surgeons. She explained that everything went smoothly and that he was fine and recovering in ICU. It turned out that most of his bowels were in his chest and they managed to close the hole in his diaphragm with stitches. No patch was needed which was a good thing, as it is more likely to happen again if they use a patch.

I called Sharon to give her the good news that Cody had come out of surgery and was doing well. I was finally discharged early afternoon and had to go down stairs to the discharge lounge to wait for Sharon. When we got over to Sheffield Children's hospital we rushed over to ICU to see our little fighter. He was in a room by himself in the corner of the ICU. He was fast asleep and recovering well.

It was Thursday 14th November when they took him off the ventilator and he went straight on to oxygen. My family had come that day to see him as well and was very happy to be a part of this major milestone. Sharon and I got to hold him for the first time. Cody was transferred over to the neonatal surgical unit (NSU) the same day.

Over the next few days our little lad went from strength to strength. Four days after he came off the ventilator Sharon and I were able to put him in a sleep suit for the first time. I finally felt like his mother being able to take care of him and cuddle him. Six days after he came off the ventilator, he took his first bottle. I was so proud of my little boy.
We got a call out of the blue early Monday 2nd December from a nurse over at NSU asking if we would like to take Cody home.

He is now nearly four months old and is doing ever so well. You would not even think he went through such a terrible time when he was first born.

When Sharon is at work Cody and I often go out down the road to our local shops and children's centre. He loves being in his swing but best of all he loves it better if you carry him everywhere with you. He also loves the TV and I often like to sit and watch with him. I will have him on his play mat and instead of playing I will often find him watching TV too and if I dare turn it off he screams the house down. He is a very chatty little lad and I will often sit him on my lap and talk to him while he babbles away. He still regularly goes to Sheffield Children's hospital for checkups and to see the Respiratory Doctor and will do for a few years yet.

Eileen Purves

I am 54 years old and from Newcastle and here is an abridged version of my story:-

For about 15 years I suffered lots of different issues e.g. breathlessness, pain down the right side of my abdomen, severe reflux and a peak flow of 150 to name but a few. Even the fact my diaphragm was in front of my heart did not set alarm bells and everything was 'just normal for me'!

In May 2011, I had 24 hours in extreme pain with two calls to the Docotr on call overnight without a visit. By mid afternoon I started vomiting blood and could not straighten up due to the pain.

Eventually, a Right sided Morgagni Hernia was diagnosed and corrected - lots of professionals were interested at this point!

I was discharged after about 10 days but re-admitted a few days later as I was in pain again with a fluctuating temperature. The Doctors aspirated my thoracic cavity and I was transferred to the Freeman Hospital. There, I had to undergo another three lots of surgery to clean out an infection. I was seriously ill with a blood count of 6.1.

I got home for good at the end of August that year but it took me about 12 months to totally recover from the trauma.

It was at this time that I discovered CDH UK who have been a font of knowledge and a great support. I feel that I know just about everyone personally and love seeing all the little miracles thriving after such a rocky start in life.

I have met a couple of mums who have CDH children and helped out at their fundraisers, which I love doing as I feel they not only raise necessary funds but raise much needed awareness of the condition.

Thank you all for YOUR hard work!

Ellie Cousins

At 9:11pm on 19th March 2012, I was handed the most beautiful baby girl I had ever seen. With two older boys at home, our family was complete but our happiness was short lived as Ellie was struggling and working hard with her breathing and taken to special care. An x ray revealed a large shadow on her right lung, which was treated as a possible infection/fluid and IV fluids and antibiotics were started She was also on oxygen.

On the third day, an ultrasound scan showed the shadow was in fact her liver and that night she was transferred from Shrewsbury maternity to Birmingham Children's Hospital for surgery. We had never heard of CDH and were devastated at the thought of our precious girl undergoing surgery but there was no choice.

It was explained that they would move the liver down, repair the diaphragm and her right lung would inflate normally. Her surgery was scheduled for 26/3/12 when she was seven days old. We were told the surgery was fairly straightforward and would take more than one hour but less than three. The day of the surgery came and I can honestly say handing her over and kissing her when she was anaesthetised was the hardest thing I had ever done.

We went out of the hospital but could think of nothing but Ellie and as the hours ticked by, panic set in. She was away about six hours and the nurses had no update and I feared the worst and was a complete mess.

Eventually, the consultant came to find us and explained that Ellie's case was far from straightforward. They had four surgeons working on my tiny baby, one of whom had been called in. They explained that they could not move Ellie's liver and they really tried but it would not budge. Her right lung was not there, only a small amount of the top lobe, and they had found a little bit of lung under her liver, which had been cut and tied off.

Ellie had effectively re-wired herself! She came back to HDU and looked awful, with a chest drain and wires and tubes everywhere. I was so relieved to see her but so frightened at the same time.

Over the coming days, she was in pain and I was constantly asking for more pain relief for her but we were assured she was doing well and the next hurdle would be to try to get her feeding.

I was told I could not breastfeed as it would be too hard work for her but I continued to express, the only thing I felt I was doing for my baby. Ellie continued to do well, amazing everybody and we were eventually transferred to our local hospital. Several more weeks passed, Ellie got stronger and we learnt how to feed her using the NG tube and administer her medicines. After a few practice afternoon visits we were allowed home.

So many mixed emotions; elation and fear all at the same time but it was so nice just to be all together. I felt so torn being in hospital with Ellie. I could not leave Ellie but I missed the boys terribly; they were my children too and I was worried about the damage this situation was doing to them.

When we got home a whole new journey started and weekly weigh ins were so stressful. Whatever we did, Ellie struggled to gain weight and seemed to be in a negative position calorie wise after every feed. She would take some from her bottle and the rest would go down her tube but no matter how long we kept her still and upright or how slowly the milk went down her tube the reflux meant everything came back, sometimes even the tube! We were re admitted and Ellie was monitored, her medications were changed and we were introduced to the pump which meant the milk could drip

in much slower and at last the reflux was more controlled.

At around the same time a CT scan revealed the artery from Ellie's liver to her heart was very short and narrow meaning it is unlikely her liver will ever be moved to its correct position. Her consultant warned that if the artery were to burst under manipulation it would result in a catastrophic haemorrhage which we would be unlikely to get her back from, so the decision was made to leave well alone. Her liver functions completely normally, just not in the right place.

Almost a year to the day later, we found ourselves back in Birmingham Children's Hospital with Ellie in intensive care with a respiratory infection. She was back on IV fluids and antibiotics and ventilated. I really felt we were close to losing her all over again and the fear and panic set in again as a swarm of people surrounded us, bagging her face and trying to get cannulas in, but again Ellie fought hard and after a week in intensive care we were transferred back to our local hospital.

Fast forward and Ellie is a healthy (most of the time) happy two year old. The significant sized hole in her heart has closed and she is developing normally. We still have the task of trying to get her eating and off her feeding tube and we also see a separate consultant at the Orthapaedic Hospital for her Scoliosis (2 of her ribs have fused together on the right, following her initial surgery) meaning her spine is curving. The fact we have our beautiful girl at home, bossing her brothers around, is a time we were not sure we would ever see and for that we will be forever thankful.
We did not know about Ellie's CDH before she was born but hopefully her story will give hope to others and as I used to whisper to Ellie "rest well, dream big and fight bloody hard sweetheart" and thankfully she did!

George and Irene

Some extracts from my diary of George's CDH Journey

30th Jan 13

Becky's first Scan today, was told it wasn't very clear and she had to go back for a more in depth Scan.

5th Feb 2013

Second Scan. We were told the picture still wasn't clear so Becky had to go back for another Scan (Alarm Bells were ringing in my head).

21st Feb 2013

Another Scan and at last some answers the doctor suspects CDH. We were given a little explanation and told not to look it up on the internet until it was confirmed (but of course we did and wish we hadn't)

29th March 13

After another Scan and what seemed like eternity, CDH was confirmed. My little grandson was predicted with a 30% chance of survival, many syndromes were mentioned and then the offer of a termination . Not a chance of that happening we have to fight this.

I trawled the internet for some answers as to why it had happened, what had caused it and ended up reading some very sad and scary stories but I carried on reading. I needed to know as much as possible about CDH, its outcome etc not just for me but so we as a family could give Becky the support and help she might need.

I came across CDH UK and I read the pages on that site I got in touch with them and they directed me to a facebook page which was for expectant mums and new parents. It was through this page I acquired a new extended CDH family. These ladies welcomed me with open arms and it was because of them sharing their feelings and stories I and my other daughters were able to give Becky the support she needed. I take my hat off to you all.

9th June 13

Collected Poppy, Becky's one year old daughter, to bring her back to Essex to live with me, whilst Becky got some rest, ready for George's arrival.

15 July 13

George is born one week before his due date. Time for me to once again call in the support of the lovely ladies, who have been sharing our Journey for the last nine months. So many ups and downs.

24 July 13

George is strong enough for the operation, it took 5 hours! One day I would write how well he was doing and within a couple of hours that would change. The ladies were there again for us.

26 August 13

George came home. His Journey continues and so does the support of CDH UK. Without them I think I would have gone insane and not just for the emotional support but financial, in the way of reimbursing some of the fare costs. So for me CDH UK is invaluable.

Finlay Peacock

On 9 March 2014, our son was born with an undiagnosed left sided Congenital Diaphragmatic Hernia. He was born by emergency C-section at Exeter R, D and E Hospital. Finlay was then transferred to Cardiff University Hospital to have his surgery. I was too unwell to be transferred and remained in Exeter while Dad traveled to Cardiff to be with him.

On the fourth day, I was discharged to Cardiff Hospital and was able to be with my son. On the sixth day of Finlay's life, his surgery was performed. He remained stable and in intensive care at Cardiff for a further two weeks. Finlay surprised us all and made massive progress, tolerating his feeds and having reduced optiflow. Finlay was then well enough to e transferred to Exter R, D and E. After spending almost four weeks in hospital he has now been able to come home. We feel extremely lucky as we realize not all families are so fortunate.

Like many people, we were completely unaware of CDH but after his diagnosis I found information and stories on the CDH website invaluable. Thank you for your support.

V Peacock, Finlay's Mother

Jacob Bowey

On 22nd July 2013, we dropped our older son Sam at school in the morning and then went off to our local hospital to have our baby boy. We knew there was a 50% chance we would not bring our baby home from hospital as he had been diagnosed with CDH at the 20 week scan. At 2.59pm, Jacob was born by C-section, weighing 6lb 2oz.

He was immediately intubated and taken off to the neonatal intensive care unit – We only got a quick glance and then it was another four hours before we would be able to see him. We did not know at this point that this was the first of a great many long anxious waits to come. At a day old, we were told that Jacob was on a 'knife edge' and that the only chance was to transfer him to another hospital for ECMO. He had his repair surgery on ECMO at four days old and returned to our local hospital three days later.

In the weeks and months that followed, Jacob went through so much and every time he started to progress, something would happen to knock him back. He had pulmonary hypertension which needed treatment with nitric oxide, then he improved and the Doctors started to wean his ventilation. He picked up an infection which led to Sepsis and we had one of the many days to come where we did not know if he would make it through the day.

He pulled out his ventilator tube at three weeks old and went onto CPA P. He managed well for a few weeks but then deteriorated again. He had gone into heart failure.
Then in September, Jacob had an in depth heart scan and we were told he had enlarged pulmonary arteries and Bronchomalacia (floppy airways) and the Doctors suggested a Tracheostomy and long term ventilation. We were devastated.

So Jacob was transferred to another hospital where he had his Tracheostomy but even afterwards the Doctors struggled to stabilize him. In December, Jacob had heart surgery and this was at last the turning point and things started to improve.

On Christmas Day, we got to take him off the ward for the first time for a short walk. It was wonderful! But then he picked up MRSA in his wound from his heart surgery and things were very scary again. He had several trips to theatre over the next few weeks to sort it out but eventually he was ready to move off intensive care onto a high dependency ward. Then we turned our attention to getting Jacob home and we finally brought him home and brought our family back together on 13th March 2014.

Jacob was nearly 8 months old.

We have now been home for six weeks and it is so wonderful to have Jacob at home with us at last. Life is certainly a bit more complicated now but we know how incredibly lucky we are and how easily we could have lost our amazing baby boy. Jacob is still on a ventilator and we have all sorts of medical equipment for him but we still get him out and about and are determined that he will get to enjoy things like any other baby. We just need to be a bit more organized and allow some extra time! We have had to get used to having people in the house a lot .

We have carers to help us look after Jacob, as he needs constant care due to the Tracheostomy. He is fed partly via NG tube but we are also working on oral feeding and hope to get rid of the tube at some point. We are now

working on weaning Jacob off the ventilator but it will take time.

At the moment the Doctors are saying that if he continues to do this well, he could end up having his Trachy out by the end of the year! There are no guarantees but things are looking positive, especially considering back in November it was looking like he may never come home. Our gorgeous boy's beautiful smiles make every step of this incredibly difficult journey worth it.

Jessica Wilkin

The morning of our 20 week scan, we were so excited. Like most expectant parents, we were looking forward to seeing our baby and finding out the gender.

The scan took ages but I thought this was normal as it was a detailed check. Then I heard the words "I don't want to panic you but I think there's something wrong". Tears started to roll down my face. At first I thought it was a mistake, but when we were shown the scan there was no mistaking the dark shadow of the stomach in the chest area.

We were taken into a room and a doctor explained that our baby had a Congenital Diaphragmatic Hernia and we were given a brief explanation and a leaflet. The leaflet said that babies with CDH had only a 40% chance of survival. We felt like we had been hit by a bus.

Somehow we had driven home and had the horrible task of ringing family and work to explain even though we didn't really understand it ourselves. The next day, we went to Leeds General Infirmary to see a consultant who confirmed the diagnosis and noted that our baby's chance of survival was 15-20% due to the amount of organs in the chest area and that it was identified at the 20 week scan. Our hearts sank and I burst into tears. We had only just got our head around 40%. We were offered an amniocentesis, as we were told there would be zero chance of survival with other complications. We were given a few days to decide whether to proceed with the pregnancy or have a termination due to the procedure being more evasive after 22 weeks.

We took the week off work to process all of the information we had just heard. We were really looking forward to our 20 week scan and it turned out to be the worst day of our lives. We took it in turns to break down. We had little sleep and went for long walks. I spoke to ARC (Antenatal Results and Choices) who were fantastic. They put me in contact with a lady who had decided to terminate after finding out her baby boy had heart conditions which would have left him hospitalized for the majority of his life and noted that for her the quality of life for the child was the key decision factor. The lady explained that it wasn't that her baby was not wanted and it was the love for the child that made her decision.

We knew that the quality of life for CDH babies was generally quite good, so it was mainly a decision whether we were strong enough to go through the full pregnancy with the knowledge that it was highly likely that our baby would not survive. We watched clips from the One Born Every Minute episode and the way that Hayley and Pete portrayed themselves helped inspire us to continue. We agreed that we should try to not get upset all the time or feel sorry for ourselves (although we did have our moments) as this would not change things nor would it be healthy to any of us, including the baby. We also agreed to talk to each other no matter what we were feeling at the time. Our attitude was to be positive but realistic as to what was about to happen.

Being part of the CDH UK HUGS group really helped us prepare for the birth. It was a shock the first time we saw a photo of a baby in ICU ventilated or when we found out that the first time a couple held their baby was 3 weeks after they were born but all of this prepared us for our journey. After following other babies journeys, it used to really annoy us when people would say to us "your baby's going to be fine, I can feel it or I just know it", having no concept about what was about to happen. We kept telling ourselves that they mean well and are trying to make us feel better.

Once Jessica was born, we stopped ourselves from getting too excited when she was doing well as we had seen many other babies do well and then drop suddenly. Thankfully, Jessica was one of the lucky ones and is now a healthy and happy baby girl. We are very grateful to CDH UK for helping us through the most difficult period of our lives and for keeping us mentally strong.

Claire Wilkin

Mollie Sandom

My little girl Mollie was born on the 29th March, one day after her due date. We were unaware she had CDH.

I had such a straight forward pregnancy and nothing was picked up on our scan, so when she was born it was quite a shock. She was taken straight to special care at Ealing Hospital and after seven hours, was transferred to Chelsea and Westminster.

I finally got to see my baby properly once I had been discharged and was so upset to see her hooked up to so many machines and a ventilator. At this point I had no clue about CDH. I had never heard if it. The doctors explained what was happening and told us she had 50% chance of survival. I was heartbroken.

Mollie was my first baby and this was not what I was expecting to happen. We had a nerve wracking few days and after sitting beside her incubator for nine days, she was finally taken into theatre to have her repair done. All went well and they were able to do it with keyhole surgery. By the twelfth day, Mollie was breathing and feeding alone which was only three days after surgery! It was like a miracle.

Finally seeing my baby girl awake and moving was amazing! She stayed in ICU for another few days then went to HDU for a day. She then went to Special Care for two days then after three weeks she was allowed home! We have been home just over a week now and Mollie is doing brilliantly.

She was 6lb 9oz when she was born but now after a month she is up to 7lb 12! She loves her milk! She's mummy's little miracle!

Suzanne Burns nee Jannaway

I was born on the 23 December 1974 weighing in at 7lbs 10ozs.

At first all seemed OK but after a short time my breathing sounded as though I was gurgling. Water was drawn off and I was sent to intensive care for the night.
I was kept in an incubator for three days and my parents were told that I could not be touched. I turned blue if handled. I was fed by tube. As it was over Christmas there were only a small amount of staff in. After the persistence of my parents concerns and with the help of a nurse, on the third day, a Consultant was brought in and we were told that she could hear the stomach in the chest cavity and that she was to be sent to the John Radcliffe Hospital at Oxford.

On meeting the consultant (who was called out from his Christmas Meal) he told my parents that I had a Diaphragmatic Hernia. My stomach was in the chest cavity and had pushed one lung right up with the other with less than a quarter left. When operated on we were told that he had taken out all her internal organs and that they were good. We were told that they only knew of one other in the country that had received this type of operation.

My scar was held together with weighted medallions. I was on a special plate which totally monitored me and was also on a ventilator with 24 hour care. In total I was in hospital for six weeks.

The consultant told us that we might have to wrap me up in cotton wool and that very often it comes in threes. At four months I had to go back for another operation, as I produced a lump in my abdomen which was a Spigelian Hernia.

I developed normally throughout my childhood. I was always conscious of my scars. Mum and Dad showed me the emergency Baptism certificate that I had before my operation and I was always fascinated by the picture of poorly children going towards Jesus.

A nurse also made me a small cuddly toy and I still have it too this day. Over the years seeing Doctors for just normal complaints, it surprised me how few knew what my scars where for.

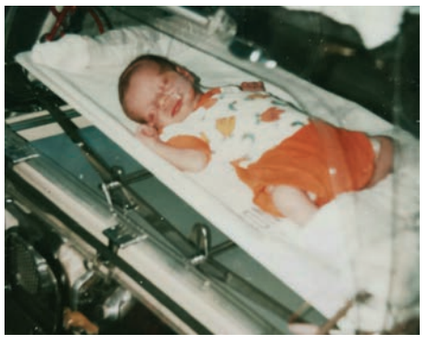
I have had a beautiful baby girl who is now 11 years old, I had a normal pregnancy, I had a few extra scans than normal and went full term.
Growing up I was quite a fussy eater and always slim as I always said I enjoy food but it does not like me. As an adult I was suffering more and more from indigestion and was getting through rather a lot of indigestion tablets, I went to the Doctors about it quite a few times over the years. It wasn't until four years ago, when I also mentioned my back being sore, that I was sent for a scan. My gallbladder was about to blow. My Doctor put me in touch with a fantastic surgeon and I went for my operation. I ended up being in the operating room for over six hours and it ended up being a complicated removal with my gallbladder in a difficult position.

Where I had lots of scar tissue inside from my operations as a baby, he had to perform surgery on my bowl and liver to remove the stuck tissue. My surgeon also gave me a colonoscopy check, which was a blessing in disguise as I had a lump removed.

I have had several checks since and all is OK and I do not need to be checked again for a few years. It was quite a shock when I came round. I was in hospital for over a week and then was off work for over two months. I had a big suture inside holding me altogether which was quite painful. Luckily I have recovered really well and was also able to have my suture out 18 months after the original operation albeit he has promised me he has given me very strong stitches! Since then I can eat almost everything with no problems and really enjoy my food.

I used to be a big fan of Holby City but stopped watching it after my operation. One evening, I was flicking channels and picked up the story about the baby that was due with CDH. I was shocked to then discover the current survival rate. I know I am very lucky to be here and am looking forward to my big 40 in December rather than having a midlife crisis (although I might just a little bit!)

George Wiggins



George was delivered by caesarean section, due to previous difficult births, at 09.40 on 25th July 1979, at Canterbury Hospital, Kent.

Due to George having breathing problems, he was taken to Intensive Care so that the problem could be assessed. After approximately two hours George's breathing appeared to settle, and the doctors and nurses felt that he had got over any problems. They told George's father that he could leave and let all the family know that things were fine. However, within an hour or so George's condition deteriorated, and George's father was recalled to the hospital. It seems that one nursing sister had seen one case of CDH before in her career and had suggested to the doctors that maybe this was George's problem. After further examination the decision was made to transfer George to Great Ormond Street Hospital.

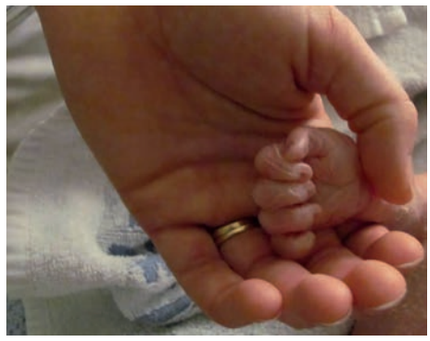
George was christened at Canterbury Hospital, in the presence of his Mum and Dad, prior to his departure to GOSH. George left Canterbury at around 14.00 in an ambulance, with his father in attendance, with all lights and sirens going. At the outskirts of London the ambulance was met by a police car escort which preceded them all the way to GOSH. They were magnificent and even managed to halt all of the traffic at the large roundabout at Elephant and Castle to ensure a clear passage to the hospital.

George arrived at GOSH at approx. 15.40 and was on the operating table by 16.15, the doctors having said that they could not predict the outcome at that stage. Luckily the operation went well and George's father could return to Canterbury Hospital later that evening, to tell George's Mum that the doctors were hopeful of a good outcome. George was well enough to leave GOSH eleven days later.

At the age of approximately six months, George suffered adhesions due to operational scarring, and was re-admitted to GOSH to deal with the problem. Throughout his childhood George had numerous periods of time in GOSH and St Thomas' Hospital, London, due to severe bowel problems.

However around the age of twelve, as some doctors had said might happen at puberty due to the arrival of testosterone, George's problems disappeared, and since that time he has led a full and active life.

Wilfred Wright



Our son Wilfred was born on 22nd August 2013. He had been diagnosed with left sided CDH in April 2013 when I was 15 weeks pregnant. Like most CDH expectant parents we spent the months that followed in a blur of hospital appointments, endless scans, amnio testing, notebooks of questions, a maze of new facts and figures and new words and acronyms to learn like LHR, FETO and ECMO. We were given varying percentage survival rates over the months and every appointment these seemed to drop and drop.

Carrying a baby through a pregnancy, that at the end of the day, regardless of these percentages, has a 50/50 chance of survival and will have to be rescued from death at their birth, is desperate. With strength, a fighting attitude and outstanding support from CDH UK, we got ourselves mentally prepared and ready to meet our baby boy. We had prepared ourselves for the time we would first meet Wilfred, when he would be in intensive care, covered in tubes and

surrounded by beeping machines. I had walked through every step in my head, the room full of Doctors and Nurses, the fact that I would not get to hold him straight after birth and the rush to save his life.

Sadly, our baby never made it to this stage. We discovered Wilfred had died on the 20th August 2013 at about 6pm. I delivered him naturally two days later at 2.34am on the 22nd August and it was both the happiest and saddest moment of my life. A moment I will never forget and still to this day is my most precious memory. For that I am so thankful.

The minutes, hours, days, weeks and months ahead were agony. They emotionally and physically hurt. I think, although others may disagree, we seemed calm and in control, very together and aware of the reality. In fact the opposite was true, we were absolutely lost. After 14 years together and almost 7 years married we were now the closest we had ever been and we got through those early days and weeks both as a team and as best friends. Nothing whatsoever can prepare you for losing your child. However, we didn't just lose Wilfred, we lost our hopes and dreams and we lost our future. Our future as a family and the start of a new chapter in our lives.

What I definitely had not prepared myself for was what was to come after the goodbyes. Once we had said our goodbyes to Wilfred, once we had dealt with telling our family and friends, had a private cremation, and held a church service for family, what was next? Well we have no other children so it seemed to be business as usual, back to normal. But the problem was we did not want to return to normal, we did not want our life as before. Andrew had to look after his business; we had to pay the bills. But I did not have my baby to look after. Friends and family rush to help with offerings of walking the dogs, bringing food over, cleaning the house but what use was that to us, we couldn't just stare at the wall.

I was not the same person as I was before so how could life just be as it was. My whole life had changed but I had nothing to show for it but memories, photos, a memory box and some of my son's ashes I decided to keep. I did not want to return to normal and be who I was before.
I spent the months after Wilfred died telling anyone and everyone about him. I remember buying jeans soon after and while a shop assistant talked me through the styles of jeans she mentioned that she had had a baby recently, so I jumped in saying that I had too and before I knew it she had asked how old he was. I told her that he had died. I didn't feel guilty though; I was and still am very proud of Wilfred. I just couldn't bear for people to think I was not a mother. I needed the world to know.

A great friend once told me I had to find my 'new normal'. This made so much sense to me and so I began my journey to discover this 'new normal' of mine. Will there be more children? I can't see into the future so I don't know for sure. Will I be happy again? Yes I believe I will. Why? Because I will find my 'new normal' and that will include my son Wilfred. It will include those family and friends who can talk about him and make him a part of our everyday lives, not just a once a year celebration.

We are Amelia and Andrew, we are a son and a daughter to our parents, a sister and brother to our siblings, an aunt and uncle to our nieces and nephews, a Director of Rowing and a Managing Director at work but most importantly of all, what we want to be known as more than anything is that we are Wilfred's Mummy and Daddy.

CHRISTMAS IS COMING FOLKS!

We have some Christmas items for 2014 that can be found on our ebay 4 charity shop along with all of our other awareness items. As you can see we have a new Christmas card design, a beautiful nickel plated CDH symbol Christmas tree decoration (which can also be engraved) and Santa Sacks, complete with the CDH symbol.

Our 2015 Calendar will also be available shortly and we would like to thank all of the families that have sponsored it, along with the main sponsor this year: 'Flawless Beauty' of Aberdeen.

Thank you also goes to Aspen Marketing who have designed and produced the cards.

By buying any of these items you can help CDH UK make a BIG difference. Simply go to www.cdhuk.org.uk, click on the 'Support us' button and then 'shop now'.

Thank you for your support.

DISCLAIMER

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

cdh UK The Congenital Diaphragmatic Hernia Charity

Useful websites

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

CDH Australia
www.cdh.org.au

Asthma UK
www.asthma.org.uk

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

Child Bereavement Charity
www.childbereavement.org.uk

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

CDH UK webshop
www.spendandraise.com/cdhuk

Medical Research Articles
www.pubmed.gov

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

Bounty - Support for new parents
www.bounty.com

Birth Defects Foundation
www.specialsource.org/condition_results.cfm?condition=2169

British Heart Foundation
www.bhf.org.uk

CDH UK my charity page
www.mycharitypage.com/cdhuk

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