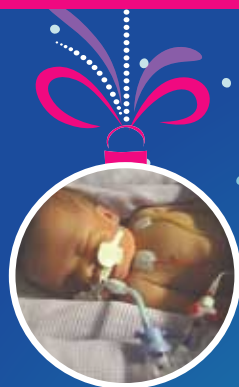




cdh UK

The Congenital
Diaphragmatic
Hernia Charity

CDH The hole story 2019 • THE OFFICIAL CDH UK NEWSLETTER



Hello from our new Chairperson!

As I write this for our newsletter I am watching a programme featuring charity volunteers who work at Christmas to help others and I would like to start my first ever Chair's welcome by thanking our own volunteers, who sacrifice their time and energy to help support our work and families affected by CDH all year round. They really do a fantastic job.



Beverley Power

As some of you already know, our founder Brenda has volunteered for 25 years as Chairperson and earlier this year she announced that she would be stepping down.....and that's where I come in! I have some huge boots to fill taking over the role of Chairperson from Brenda, but I hope she now can relax and spend more time with her lovely family after many years fronting the charity. I have been the Secretary of CDH UK since 2010 and so I am not new to the Charity and lots of you will be familiar with me already. I hope that I can continue to lead the Charity as well as what Brenda did and I am really enjoying the role so far. Volunteering isn't always plain sailing, but it is very rewarding and if you are interested in joining the team let us know!

2019 has been another busy year for CDH UK and we are very proud to have published our first open access research paper and completed phase 1 of our mobile app development and also announced our CDH UK PASSPORT project to help patients with transition of care. We have also made further progress with the development of our feeding leaflet that will be open to public consultation early in 2020. We also have expanded our financial schemes portfolio to introduce a new scheme specifically for counselling costs to enable us to help families with PTSD in addition to bereavement counselling.

We continue to make important contributions to research worldwide and we hope that 2020 will see further collaborative efforts. We are excited for CDH 2020 which is a conference dedicated to Congenital Diaphragmatic Hernia and we are very proud to have been invited to this event in Houston, Texas.

Thank you again for your support and amazing fundraising efforts and we hope that you will continue to support our work in 2020.

A special thank you to our Editor Tony Smith and to those of you who have shared your intimate and poignant stories; they really do help families.

Wishing you all a happy & healthy Christmas & New Year.

Beverley Power
Chairperson



Research HUB

Over the past few years we have volunteered our time and expertise and donated more than half a million pound to some exciting research to projects all over the world. Some projects are focusing on prenatal treatments to improve survival and long term outcomes and some are looking into genetic aspects. All of our funded projects are still ongoing and updates can be found on our website.

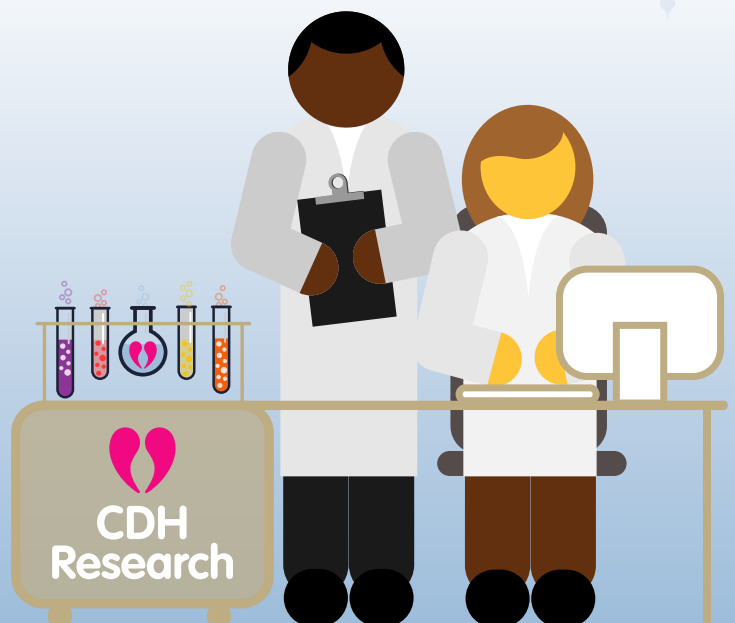
The highlight of the year was having a research paper published in an international Paediatric Surgical Journal. The research stemmed from feeding issues in CDH patients. The paper is open access, which means anyone can access it, read it and refer to it.

We also made a commitment to worthwhile research with the development of our WE CARE Research strategy. This strategy sets out the basis for our research aims and goals and ensures that we stick to it's guidelines when making decisions on in house research and funding external research projects.

Our upgraded website is also allowing us to create a new 'Research HUB' with areas for Patients and Clinicians to access our surveys and research projects and to gain access to lots of research information. We hope that this will be completed early in 2020.

Without your support and donations we simply could not fund further research, so thank you from all the team for your continued support.

CDH HAS DONATED MORE THAN
£500,000



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Research HUB (continued)

55. LONG-TERM FEEDING PROBLEMS IN CONGENITAL DIAPHRAGMATIC HERNIA: RESULTS OF THE PATIENT-LED SURVEY

Beverley Power¹, Soichi Shibuya¹, Brenda Lane¹, Paolo De Coppi^{1,2}

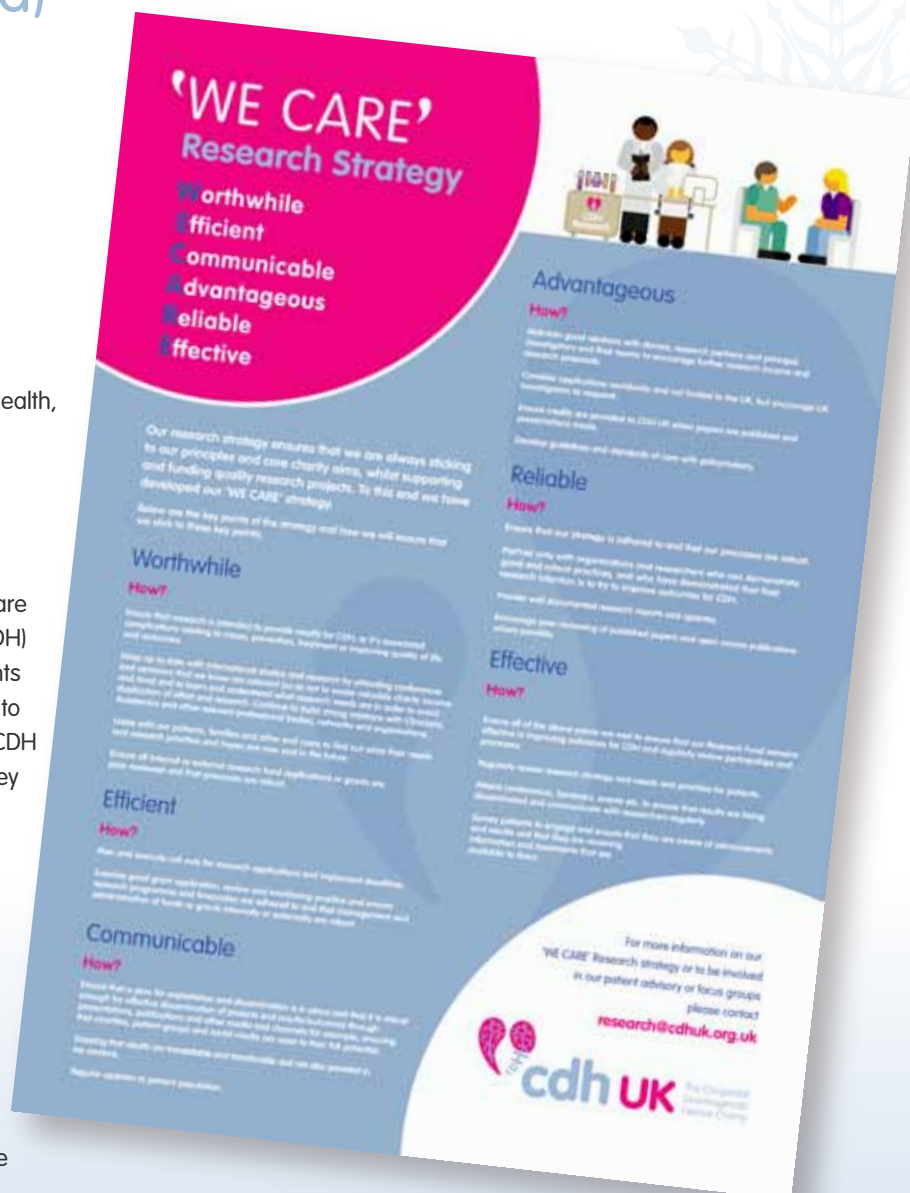
¹ CDH UK

² Great Ormond Street Hospital, Institute of Child Health, University College London

Aim of the study: CDH UK is a registered charity governed by volunteer committee and providing informal support to patients, families and healthcare workers with congenital diaphragmatic hernia (CDH) internationally. Through its network of other patients and families, it also offers information and advice to supported members and other organisations on CDH around the world. The aim of this patient-led survey was to determine the feeding problems of CDH survivors.

Methods: Answers from CDH survivors were collected through an online questionnaire (SurveyMonkey®) undertaken by CDH UK. The questionnaire contains questions about their feeding problems and support they are receiving for it.

Main Results: Overall, 151 patients answered some parts of the survey and 102 patients completed the questionnaire. Overall, 116 (76.8%) responders reported suffering from any type of feeding issue. Gastric acid reflux, swallowing difficulty, and food intolerance were the commonest symptoms experienced by 97 (91.5%), 34 (32%) and 25 (24.5%) are not. Only 36 (33.9%) responders have received any written information on feeding or details of patient/parent support. Six (5.7%) patients have ever received any counselling to their feeding issue and 5 (83.3%) of them described it helpful.



Conclusions: This is the first patient-led survey in CDH. CDH survivors frequently have various issues with feeding, which may not be adequately supported or discussed clinically. It is desirable to assist the patients to reliable resources of long term support.

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Awareness Day 2019

This year our awareness theme was centred around the challenges of growing up with CDH and we produced a short video entitled 'When I grow up', which featured children affected by CDH. The video was a huge success and raised lots of awareness. We also held a 24 hour Jokeathon to raise funds and the best joke won a prize of a £100 Amazon voucher. CDH UK would like to thank all of you who helped to raise awareness and funds during June. This is a key part of our annual drive to raise the profile of CDH and CDH UK.



Keep checking our website and social media pages for details of our 2020 awareness campaign!

'CDH is no Joke'



...but your joke
could help to raise awareness!

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This is not goodbye!

25 years ago Brenda & Kevin Lane's Daughter Alysha was born with Congenital Diaphragmatic Hernia. They hadn't heard of the condition and could not find any parent support in the UK and so as a consequence they set up a small support network from home to help other families going through the same diagnosis. Ten years later and with the help of a local market trader's association donation and other families in the UK they formally registered their network as a Medical Charity.

Brenda has run the Charity for 25 years and has carried out the role of Chairperson since the charity was registered in 2004 and due to personal reasons she decided after so long as Chairperson it was time to step back and let someone else take on the role so she could take a well earned rest from the responsibility of heading up the Committee and to spend more time with her family.

Our Secretary Beverley Power was nominated as the new Chair and took over the role in May 2019 for a period of 12 months. Committee member Katie Chapman takes on the role of Secretary. Brenda stresses that she is not leaving the charity and will continue to be a Trustee and volunteer Committee member.

Brenda was presented with a lovely keepsake picture and clock to remind her of how valued and important her work and input has been over the past 25 years and we hope that she continues to volunteer for CDH UK for many more years! Thank you so much Brenda from us all!

We would like to wish our new Chairperson Bev and Secretary Katie all the very best in their new roles.



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Family Get Togethers

We held a total of four Get Togethers during 2019 where we got to bring families old and new together for support and a great family day out. The first of the year was held in Lancaster in the North of England, the second was in Edinburgh, Scotland, the third was in Dublin, Ireland and the final one in Cardiff in Wales.

Our Get Togethers cost around £500 per event to host which covers the cost of venue hire, catering, play equipment and craft materials, insurance and volunteer expenses. Sadly, we have in recent years had to charge for tickets due to people not turning up and failing to notify the charity or host family. We are looking for ways to improve our Get Togethers. We do try our best to hold as many as possible to enable more families to attend but this ultimately relies on volunteers and donations.

We would like to thank the following families who hosted our 2019 meetings:

Stephanie Colwell
Ruth Docherty
Ciara Barrett
Joanne O'Sullivan
Rickie & Samantha Gray

We hope to meet you at one of our 2020 Get Togethers!

If you are interested in hosting a future Get Together in your locality please get in touch by emailing support@cdhuk.org.uk



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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.

Charley Jaye's CDH story

We gave birth to our first baby, a beautiful baby girl on the 11th August 2017. We stared lovingly at our baby for some time after birth before she was taken away for what we thought were normal newborn checks. The next time we laid eyes on our precious girl she was in an incubator with wires and machines coming from her tiny body. We got the dreaded news that Charley Jaye had LCDH. We had never heard of this condition before and were bluntly told to never Google it. We were told she would need an operation for a chance to save her life, which she had on day 5. To cut a parent's worst nightmare of a story



short she recovered absolutely amazingly and is now a super smart, loving and hilariously beautiful 2 year old who rocks her scar. To mark her journey and the scar that saved her life her daddy had her scar tattooed in the same place on his stomach.

This year our baby became a big sister and ironically Georgia Leigh K was born on the 28th June 2019 - CDH Awareness Day!

Their bond is fantastic and we are such proud parents.

Always keep positive and stay strong



Here are our girls meeting on CDH awareness day



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Cody's CDH story



When I was 14 I found out that my mum was pregnant again, my brothers and I were absolutely delighted. We couldn't wait to tell everyone that we were getting another younger sibling. I was over the moon because it meant that I would have another little baby to help take care of. Little did we know that this baby would have a huge impact on all our lives forever.

The day after my mum told us we went to my grand-parent's house and told them, then we told the rest of my family. Everyone was so thrilled and could not wait for the baby to arrive. However, at my mum's 20 week scan the doctor found something wrong with the baby. The doctor told my mum and step-dad that the baby's heart was slightly pushed to the right, this of course caused them to start worrying about the baby. 2 days later they went back to the hospital for another scan, they were told that the baby's bowel was up in its chest. This is known as CDH (Congenital Diaphragmatic Hernia), where the diaphragm does not develop properly or does not form at all, this causes the baby's other organs to move up through the diaphragm into their chest, which is what happened with my younger brother.

The day of the scan I was away on a school trip to the Cairngorms and had no idea that my mum was even going to the hospital again as she had kept it a secret from everyone. When I arrived home my mum told my brother and I that she needed to talk to us about something, obviously this caused me to start panicking, wondering what I had done wrong or what we were going to get into trouble for now. She took us upstairs and told us "the baby's heart is pushed to the right and his bowel is in his chest. He has a 50% chance of surviving". At this moment, I was so shocked that I couldn't even say anything and didn't know how to react, this was my unborn baby brother and all I wanted was for him to be safe and healthy. I remember this day very well as it started out being an amazing day away having lots of fun with my friends and ended up being one of the worst days of my life. That night I didn't do much sleeping as I kept breaking down into tears every time I thought about it, I spent most of the night just sitting there thinking about the fact that there was a chance I would never get to meet my baby brother. Thinking about this absolutely killed me but I had to stay strong for my mum and step-dad as it was already hard enough for them to deal with.

The next day was a blur, I went to college as I normally would on a Friday but I just couldn't concentrate on anything as all I could think about was whether my brother was going to be alright or not. I spoke to my friend Daniel about it and he told me not to worry and to just believe that my brother would be strong enough to pull through this. I felt much better after talking to someone about it and being able to get it off my chest however it did still bother me.

The next few months passed by very quickly, my mum continued to have regular check-ups at the hospital and was told that the baby was doing well and all his other organs were developing fine. Before we knew it, it was the 14th of March 2016 and my mum was going into the hospital to get started off. That morning I was so anxious and scared knowing that once she had dropped my brother and I off at school we wouldn't see her again until after the baby was born. I went into school and got on with my day as I normally would, constantly checking my phone to see if my mum had given any updates on how she was getting on. That night I had to go to my cousin's house as it was his birthday, everyone in my family was excited and anxious waiting for updates from my mum to find out what was going on, however, nothing happened until the 16th.

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Cody's CDH story (continued)

Just before break time on the 16th I looked at my phone to find a message from my step-dad saying that the baby was here and he was in the neonatal unit of the hospital. That night we went to the hospital to see mum and the baby, I couldn't wait to finally see my mum again. We were told that the baby was doing good and that we could go down to the neonatal and see him, I fell in love with him instantly but it broke me knowing that I couldn't even touch him or hold his hand. Looking back now I can't believe how strong he really is, he's grown so much since then and now you can't even tell that there was ever anything wrong with him.

Two days later he got his operation to fix his diaphragm and move his bowel back down, I was so worried about this but everything went as well as it could have and he was back in the neonatal unit kicking his legs straight after his operation. We weren't allowed to visit him until the next day as the nurses wanted to just let him relax after his operation. The next day we went in to see him and I couldn't believe how different he looked already, he looked so much healthier and his stomach wasn't going in as far anymore because all his organs were in the right place.

The next few days after that were the same routine, coming home from school, getting changed, heading to Aberdeen hospital and visiting mum and the baby. However, on the 24th my mum could hold him for the first time ever when he was 8 days old. On the 25th when my brothers and I went in again we were allowed to hold him as he was no longer in the neonatal unit he was now in high dependency, as he was doing a lot better. By this point he only had his feeding tube in as he was finally strong enough to breathe on his own so the doctors removed his breathing tube. I remember being over the moon when I found out that I was able to hold him for the first time.

On the 29th of March, my baby brother was finally allowed home as he was well enough now, I couldn't wait to finally go home to my own house again and this time have a little baby with us. The whole day at school I was so excited knowing that when I got home my family would be back together again. That night I got to hold him for



the first time outside of the hospital and it was so nice knowing that we wouldn't have to travel all the way to Aberdeen to see him as he was home with us for good now. I remember this day like it was yesterday as it was one of the best days of my life knowing that my family was whole again.

Looking back at this situation now I can't believe how much it changed my family, we learned how to be stronger than we'd ever been before and that you should never take anything for granted as it can be taken away from you in an instant.

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Rosie Mae's CDH story

Rosie was diagnosed with LCDH at my 12 week scan stomach and bowel in chest and potential heart problems.

She was born by emergency c section after being induced and nothing happening 2 days after.

Rosie was born on 10th July 2019, weighing 7lb 10oz at the women's hospital, she deteriorated 4 minutes after birth and was put on the oscillator, her right lung was developed but not much of a left lung. A couple days after birth we was told that she wouldn't make it to the children's hospital Alder Hey for surgery as she was too poorly. 10 days after birth she was sent to Alder Hey and had her surgery at 18 days old, the hospital had to do the operation on the oscillator but they saved her life!

Less than a week she was off the oscillator, ventilator and just about to come off CPAP onto oxygen.

She was off oxygen 2 weeks after birth.

She was sent to Whiston Hospital just over a month of birth due to feeding as she couldn't swallow.

Discharged at 2 months old to be exact with NG tube.

Rosie is now 3 months old, the best little girl ever!

Still NG tube fed but happy!

Not the easiest start to her life but forever grateful that she's with us today.

I would love other parents to have their CDHERS survive this horrible condition that's why we need spread awareness of this to help research to cure this.

Thank you.

Jess



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Noah's CDH story

CDH Miracle survivor Noah William Scott, and his parents Alexis and Gary.

This story is told by Julie, Noah's nanny as Alexis and Gary still find it too upsetting to talk and write about.

As a mum being told your daughter has fertility problems, you blame yourself, when you have a child he/she is a much wanted bundle of joy, to make a mother so proud to call her own, you nurse them through illnesses, give guidance and support as they grow up. But the thought of your daughter never being able to do any of these is heartbreaking.

Alexis and Gary wanted to be parents so much and to do that they had to endure constant visits to the hospital, Alexis had to take lots of drugs, and have numerous scans, blood tests and operations, which they found very difficult, little did they know this was nothing to what lay ahead.

Then the news they had been waiting for, for so long, Alexis was pregnant and she and Gary were to be parents, we were so happy. On the day of the 12-week scan, I was in work and I received a call from Alexis, she was sobbing inconsolably. Alexis had had a missed miscarriage and their baby had died. Alexis and Gary would never forget their baby, now a star in heaven with nanny Avril Scott, looking down on us.

As a mum I was now deeply worried about Alexis' state of mind, she was frail, she cried continuously she shut herself off from her friends and was at an all time low, but her husband Gary proved to be her rock, looking after Alexis, bearing in mind he too was going through the loss of his child.

They both decided to carry on with fertility treatment and within two months Alexis was pregnant again and expecting her baby in June 2010. The pregnancy was kept quiet until after the twelve-week scan. The build up to the scan was difficult, with doubts as to whether the baby was still alive, and it was a worrying time for all. Who said pregnancy was a walk in the park. Alexis



bloomed and looked well so we were delighted every time she came down with morning sickness, as it was a good sign the baby was thriving. The twelve-week scan was good and we all settled in to the fact my daughter was going to be a mummy.

On the day of Alexis's twenty-week scan I was at home with my husband Tony, and grandson Caden. I asked Alexis to phone me as soon as the scan was over and I remember sitting near the phone looking at my watch, wondering why she hadn't phoned. I began to worry; Alexis always phoned me first, what was wrong? I then heard their car pull up outside the house; I jumped from my chair and ran to the front door. The door opened and I just stared at Alexis and Gary, both had tears streaming down their cheeks. There was something seriously wrong with Noah, Yes they now knew they were having a boy, but he had a serious problem he had a Congenital Diaphragmatic Hernia (a hole in his diaphragm), his heart had been moved to the right hand side of his chest and he had cysts on his head which meant there was a 50/50 chance he had Edwards or Patau syndrome. The best scenario was that would only have a CDH, but his chance of survival; they were told was just 20%. I shouted 'No, No', I burst into tears and we all sat down and cried and cried.

Research took over our lives, we wanted to hear all the good things on the Internet, and unfortunately that wasn't the case. Alexis had an amniocentesis, which was sent to Liverpool for analysis. We only waited two days for the result.

This should have been the time when most 'mum's to be were out shopping for their soon to be new babies, how different Alexis and Gary's life was going to be from theirs. Alexis had to carry on not knowing whether her baby was going to live or die.

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Noah's CDH story (continued)

Surely life can't be that heartbreaking to take two children away from a couple who had so much love to give.

Alexis and Gary went to Hospital for a meeting with the doctors and surgeons who discussed with them their role in the fight to save Noah and more information was made available to them. The Internet was also a comfort, being able to research and knowing that other parents were there to give advice or just tell their story. Facebook also became our best friend, being in contact with couples all over the world, giving Alexis and Gary the support they so needed. Alexis and Gary sent out an email to their friends and family explaining what was wrong with Noah and asking them to visit a website about a little CDH survivor called Imogen. This was to give them an insight on the long battle ahead of them.

There was a slight relief when the results of the amniocentesis revealed Noah was not suffering from Edwards or Patau syndrome.

The pregnancy was now set out to Alexis and Gary, Noah's best chance of survival was if she was to proceed in the pregnancy full term, have Noah in a specialist hospital with a vital ECMO machine, as he would not be able to breathe for himself, when stable he would then be transferred to Alder Hey children's hospital for a life saving operation to repair his diaphragm. They went for scans every 2 weeks and as the pregnancy progressed Noah's chances of survival increased to 50%.

Prior to Alexis giving birth she kept saying to me 'mum be strong and don't let me have a caesarean, no matter how much pain I am in, I have to have the natural birth to give Noah his best chances of survival'. This was Alexis fighting to save her baby.

On the morning of Wednesday 26th May Alexis went into Labour and was admitted into Hospital, the care she received was second to none. I was the proudest mum alive to see her so strong never giving up the fight. All Gary and I could do was support, encourage and give her comfort. Noah was born at

11.53pm on Wednesday 26th May weighing in at 6 lb: 13 1/2oz, Alexis and Gary were not allowed to hold their baby, but the staff did allow him to be placed on Alexis's chest for a few seconds. Then the doctors then began to treat him, they started by intubating Noah but could not get the first tube in, it was too big, we all kept looking at each other shocked, trying not to panic, the second tube was inserted within a minute, it seemed like hours, I dared not breathe as I didn't want to show Alexis how worried I really was. Successfully intubated, Noah was attached to the life saving ECMO machine and taken to ITU. Alexis and Gary were now alone without their baby.

Noah had won his first fight for survival.

I went home feeling confident Noah was definitely going to survive, BUT this was where the fight really began and little did I realise that the next few months would be a rollercoaster of tears, joy, tiredness, worry, concern and every emotion you could possibly think of.

At 10.30am on Thursday 27th May 2010, a time and date I will never forget, I was in my car when my mobile rang, I answered it immediately, Gary told me that Noah stopped breathing at 10am, he had been resuscitated but the hospital doctors were advising to have him baptised just in case it happened again and they couldn't bring him back as he was a "very poorly little boy". He asked me to come to the hospital with my husband Tony and daughter Cara, as the baptism would take place at 5.00pm.

We sat in a room and waited for the priest, the mood was sombre. When he arrived, Father Peter made us feel at ease with words of comfort, he was so sweet; he had obviously been in this situation before and performed numerous baptisms. I prayed and prayed so much for Noah's survival. The baptism was tearful and emotional; Cara and Tony had to leave the room they cried so much.

Noah had won his second fight for survival.

Within twenty-four hours Noah had started to improve and the doctors told Alexis and Gary that this was the best they could do for Noah and the decision was made to transfer him to Alder Hey Hospital PICU for the much-needed life saving operation to repair his left sided congenital diaphragmatic hernia.

At 4pm on 28th May, Noah was moved the short distance by ambulance from Liverpool Women's Hospital to Alder Hey children's hospital. Alexis and Gary were given a room at Ronald McDonald house, this was where they would live for the foreseeable future, if Noah was to survive his operation.

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Noah's CDH story (continued)

The following day at 15.52 Noah went into theatre where Mr Matthew Jones, Noah's surgeon, operated to return his organs back to their correct position and repair the hole in his diaphragm. The operation took 5 hours, the longest 5 hours of our lives. I went to see Alexis and Gary, not to talk just to be there with them, we hoped and prayed and even begged he would pull through. The operation was successful, although they had to remove his appendix as it wasn't in the right place and could cause problems later in life.

Noah had won his third fight for survival.

Whilst Noah was in Intensive Care Alexis and Gary dealt with things differently. Alexis wrote a diary and Gary wrote a poem on his thoughts and feelings, the same poem was printed on Alexis and Gary's wedding favour in October 2010.

Baby Blues

*Stuck in the hospital, nowhere to roam, Mum and Dad feeling so alone,
Thankful McHouse have given us a bed, somewhere to lay our weary head.
Sat by your bedside all thru the night, every beep giving us a fright,
When you cry it breaks our heart, only inches away but seems miles apart.
Not wanting you to be out of sight, yet unable to hold you tight,
Never knew we could love like this but only able to give you a kiss.
Counting the hours till we take you home,
The new king to the Scott throne*

I would travel to the hospital every day to give Alexis and Gary a hug, make sure they were eating and give them much needed support.

Noah had a setback in June when on two occasions his heart raced out of control a Supra Ventricular Tachycardia. He was placed on drugs and treated for a suspected heart problem.

The care in ITU was second to none; they were supportive, allowing friends and family to visit Noah. Noah had been ventilated from birth and on the 10th of June he was extubated and put on c-pap, which he removed himself after 1 hour and

started to breathe unaided. It was also the day Alexis and Gary held Noah for the first time.

I remember Alexis phoning me that night, it was the eve of her birthday she was crying with joy telling me she had been given the best birthday present a mummy could wish for. Our family got together at the hospital the next day; it wasn't a celebration for Alexis's birthday but in unity in the fight and support for Noah.

My special time came on the 12th June when I was allowed to hold Noah, my grandson. Looking at him, wires and tubes everywhere, such a precious little boy I thanked god that he was alive.

Over the next few weeks and months, Noah would endure a total of five operations, a blood transfusion, severe reflux and feeding problems. He later underwent further surgery, a fundoplication, a gastrostomy and a Mic-Key button insertion. Every time Noah took one step forward it seemed that he would always take several back. Some days we couldn't see light at the end of the tunnel. But what kept us going was Hope. Noah came out of hospital on 10th August 2010 but was re-admitted in September for 2 weeks for his fundo and gastronomy and has not been back since leaving on 17th September 2010 except for check-ups.

Alexis and Gary were married on 9th October 2010 with Noah being the guest of honour, it was the most emotional wedding have ever been privileged to be a part of. All their friends and family who gave them love and support, as when Noah was born, surrounded Alexis and Gary.

Noah is now sixteen months old, he still has problems eating and drinking and is fed through a tube, but we can now cope with that because he is alive, he is a bubbly happy little boy with lots of love to give. His CDH has made Alexis and Gary into the strong couple they are today and in August 2011 Alexis gave birth to Indi, a happy healthy girl and little sister for Noah, a perfect ending.



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Maisie's CDH story

So fed up!

It was 23rd December I was 11 days overdue and so ready to meet my baby. My midwife came out to try and give me a sweep before my planned induction Christmas Eve. But her heart rate dropped they sent me into the hospital and monitored me; no cause for concern. They managed to do a sweep and it put me into slow labour, yay! The midwife finishing at 10pm said she didn't expect to see me in the morning but 7am rolled round and I was still there! Taken up to have my waters broken they discovered meconium and put me onto the monitors, labour wasn't the best but an epidural later I was asleep at 8cm dilated. The time finally came 10cm dilated I was pushing but she just wasn't coming and my contractions stopped. why doesn't she want to come out! All of a sudden a doctor and 2 others came in.



Forceps, episiotomy but I just wanted my baby! Then there she was but she was quickly whisked away and worked on, when my mum kept reassuring me she would be okay. They said they could hear crackling on her left side and needed to take her to see if she was okay. I didn't even know what she weighed, then an hour later the worst the consultant came in and said she had her bowels in her chest a condition I had never heard of CDH she needed emergency surgery and had a 50% survival rate, only the second case he had ever seen. It was 3am Christmas day when I got to see my baby for the first time, on a ventilator looking vulnerable and little. Safe to say I didn't sleep, the team from Cardiff UHW came down at 11am Christmas day with her 'sleigh' and were super lovely as she was strapped in for her 2 hour journey. I followed behind in the car, super poorly, numb with dread. Great news she had remained stable and they're hopeful she can have surgery boxing day! The surgeon explains



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Maisie's CDH story (continued)



everything while I'm hooked up to blood transfusions after being re admitted myself. 3 hours pass, amazing she's out! And being the strong willed girl she is even pulled out her own ventilator on the operating table! 2 days later I get to hold her for the first time; the most amazing experience of my whole life. She's amazing 10 days and she's home. I can't thank the doctors and nurses enough at Cardiff UHW. And learning about a condition I didn't know existed till I had to know. Now we fundraise for an amazing charity over £200 to date. My dad (Maisie's Bampy and uncle Morgan) running a half marathon. My dad also doing 10 half marathons in a month; 1 for everyday Maisie was in hospital. My girl is now a thriving 11 month old and I can't be more thankful as our story could have been so different.

CDH survivor.



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Cooper James's CDH story



On the 6th of August 2017 our world was turned upside down. I went into labour 9 weeks early and we were trying to get our heads round that we were having a premature baby who's lungs wouldn't be properly developed and would need to spend time in the neonatal unit. While still in the recovery, after a forceps birth and our tiny 3lb 3oz baby boy Cooper James was rushed away to the NICU, 3 consultants stood round my bed and gave us the news that Cooper had been born with an undiagnosed left sided diaphragmatic hernia. It was the first time we heard those words and we felt like our world was crumbling around us. They told us he had a 50% chance of survival and that he'd need surgery if he made it and got strong enough. It was hard enough knowing that we were giving birth to a prem baby then being told this just devastated us and our families. We hadn't even held him yet as he had been rushed to the neonatal unit in Aberdeen maternity hospital to get support with his breathing for his under-developed lungs, they said he was now intubated fighting for his life. When we went to see Cooper for the first time he was so so tiny and to be told he only had a 50% chance of survival was the worst feeling in the world. How could someone so small fight this? The next morning the surgeon made the decision that he was stable enough to be operated on. Saying goodbye to him that morning broke our hearts, we prayed he'd get through the

surgery and come back to us in the NICU. Later that day he returned to the neonatal, he was still intubated and remained stable for the next few days. We lived nearly 40 miles away from the hospital and had another son, Olly, 8, who was being taken care of by our families. It was a very tough time and we spent as much time at Cooper's side as we could as well as being there for Olly too. Our little fighter went from strength to strength and at nearly 6 weeks old we were told we could take him home. We were so happy that our tiny little baby had been so strong and came through so much. He is now a very happy 16 month old doing brilliantly, meeting all his developmental milestones and smashing his surgical checks. His last X-ray showed his left lung has filled out into the space where his bowel and spleen had been squashing it. We are and will be forever grateful to all the staff at Aberdeen Neonatal Unit and to Cooper's surgeon, consultants and nurses.



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Our Fundraising CDHeroes!

We have seen some amazing fundraisers take place again this year.....from Baking to Biking and Running to Hiking, Triathlons to Marathons, Selling to Swimming, making jewellery and more!

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!

We would like to thank our Fundraising Administrator Sarah Jones, Fundraising pack co-ordinator Tracy Benson and our Awareness Merchandise Administrator Liz Precious for their commitment and hard work during 2019 along with other volunteers helping with fundraising.



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Our Fundraising CDHeroes!

We really wish we had the space to showcase all of your fundraising efforts, but sadly we don't. Whilst every fundraiser is equally important, some raise media interest and have extra community or awareness meaning. Some notable fundraisers this year have been Dan & Craig's London to Paris Cycle, Richard Slate's Marathon, Clare Plant's Test theTeam (Barclay's), Claire Dean's nomination of CDH UK and subsequent donation from Kuehne & Nagel. We have also seen some amazing and selfless fundraising acts from our young supporters such as organising school fundraisers, selling paintings, or raising funds and awareness as a community team for Citizen's Service like Natalie and friends did.

You are all amazing you really are and on behalf of everyone thank you so much!



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Our Fundraising CDHeroes!

We recently had a charity coffee morning and offered taster therapy sessions and raised over £270 for CDH UK. Our daughter was born with CDH in January, postnatally diagnosed.

The local paper did an article about her to raise awareness of the condition.

Thanks, Lisa.



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Our Fundraising CDHeroes!

We are constantly asked if we have places in the London Marathon or Great North run up for grabs and normally the answer is no (sadly). Places are very difficult to obtain and are usually won through a ballot system. If we won any places we would advertise them on our website and social media pages. You can however enter the ballot as an individual and if you are successful we will provide you with a running vest and other items for the event. However, as we know what keen runners some of you are, last year we purchased 5 places in the Asics London 10K and 5 CDHeroes took up the challenge!

Thank you Chris, Chris B, Dean, Michael, sadly Nathan had to pull out of the event at the last minute.....we hope to have places this year too so if you are interested please register by emailing fundraising@cdhuk.org.uk

Here are some pictures from the 2109 Asics London 10K.



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Projects, Conferences & Collaborations

We continue to work hard on new and exciting projects and none more so than our CDH UK Mobile app. We have now completed Phase 1 of the app build and hope to have a draft version of the app available to test during the first half of 2020. We want to make sure that the app is both useful to patients, parents and Medical professionals and that it works well too! This is a major investment of time and donations and so we want it to be the best possible investment.

We also introduced our PASSPORT project aimed at the transition of care from Paediatric Services to Adult Services for patients. We expect to form a focus group in 2020 to develop the project further and to host a Stakeholder meeting. Watch this space!

Attending Conferences can be costly and so we carefully choose what we attend and which event we will gain the most benefit in terms of information and networking, or where we can make the most impact in delivering information. This year we were again invited to speak at the BAPS congress (British Association of Paediatric Surgeons) and also for the first time at the BAPES Congress (British Association Of Paediatric Endoscopic Surgeons). We also showcased our important work at various hospital study days and attended the World Fetal Medicine Foundation Congress.

We continue to be an expert patient representative on the GIFT-Surg project and a member of SCANS and we represent the patient on a Data Safety Monitoring Committee.

One of the most important events for the charity, which takes place every couple of years is the CDH Workshop, which is headed up by the International CDH Study Group and The CDH Euro Consortium and is attended by Medical experts in the field from all over the world and importantly includes patient organisations too. The last one was held in Liverpool and was sponsored by CDH UK. The event in 2020 will be held in Houston, Texas in the United States.

2020 will be an extremely exciting year for CDH UK as we see our current projects move forward and we prepare to release details of an important data collection project.



Our Collaborations with other charities and organisations both in the UK and internationally continues and we welcome the opportunity for new collaborations in the future. A list of collaborations can be found in our research CDHhub together with research updates.

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3rd Annual ERNICA Meeting

In April 2019 we attended the third ERNICA meeting in the historic city of Padua in Italy. This had a particular interest for us this year as one of our Patrons Professor Paolo Di Coppi studied at the world famous Padua Medical University where the event was held and one of the earliest cases of Diaphragmatic Hernia was also noted here.

Within the coming year it is planned that this group will start setting up training days for pre-natal assessment for diaphragmatic hernia. The programme was presented by Professor Jan Deprest (CDH UK Patron) and Professor Alexandra Benachi. There will be two training sessions a year in Paris/Leuven. The proposal for the development of a Core Outcome Set for CDH was also presented and interested ERNICA members were invited to participate. Over the coming year continued efforts will be made to set up a prenatal network involving specialists from all ERNICA. An overview of research activities within the CDH/AWD workstream and proposed the development of consensus statements for abdominal wall defects.

Beverley Power, patient representative for CDH/AWD, presented the newly established 'Alliance' for international CDH/AWD charities. This was promoted as a potential blueprint for other diagnostic groups. The IDEA alliance is a group of patient organisations from around the world who strive to support patients with Congenital Diaphragmatic Hernia, Congenital Hiatus Hernia, Eventration of the Diaphragm, Gastroschisis and Omphalocele and improve outcomes and patient

experiences by increasing awareness, improving education and stimulating research: <https://www.idea-alliance.org/>

Beverley also presented the results of a survey she circulated to patient representatives prior to the meeting. The responses provided an insight into the experiences of patient representatives within the network and many ideas were given in regards to strengthening patient involvement. These results will help to inform future ways of working.

The ERNICA clinical exchange programme was presented. This training programme will be launched in summer 2019 and will be open for fellows to apply for short stay visits in ERNICA centres. ERNICA will also start hosting educational webinars over the coming year. Dick Tibboel then outlined the roles and responsibilities of the Scientific Committee and promoted research collaborations within ERNICA.

Gunnar Aksnes (new coordinator for Standards of Care) closed the meeting with an overview of planned efforts regarding the implementation of ERNICA developed/revised/adopted guidelines within ERNICA centres.

Despite the UK set to leave the EU, CDH UK will continue its work as a patient organisation with the European Reference Network and will carry on its work and collaborations within Europe..



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Snowflake Appeal

Our Snowflake appeal has been running for a few years now and always goes down a snowstorm with families who want to include fundraising and awareness in their festive celebrations. Each year we release a new decoration for you to collect.

For 2019 we have released another tree decoration, which is a lovely quality perspex decoration with a window in which to place a photograph. These are ideal for family photos, pictures of loved ones no longer with us, or pets. You can order these via our website ebay icon link, or by clicking on any associated link on our social media sites.

All proceeds from each snowflake are donated to CDH UK.



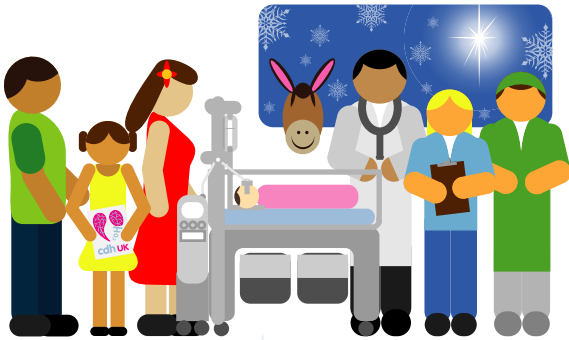
cdh UK The Congenital Diaphragmatic Hernia Charity



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Colour in Nativity Scene



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CDH UK Christmas Word Search



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

tinsel
sack
lights
twinkle

rudolph
glitter
angel
star

stocking
presents
santa
tree

sleigh
christmas

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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Hernia Charity

