



cdhUK

The Congenital
Diaphragmatic
Hernia Charity

Ho, ho, ho and welcome to our 2016 Christmas newsletter



It is so nice to get a chance to speak to you all and to tell you how thankful we are that we have had so many great fundraising events from you all over the last couple of years.

Your determination and ingenuity never fail to impress us all here at CDH UK. Thanks to you all, our research total now stands at **£475000!!!**

Which is absolutely amazing. It means that we can at last now start to take part in some meaningful research.

Our first small item are FETO balloon packs for University College London Hospital, so that they can be the next centre to carry out the FETO procedure along with King's College Hospital, under the conditions of the TOTAL randomised controlled trial so that more patients can be treated.

We also have other longer term trials which we are planning to fund with this money. We will be able to tell you about these very shortly, so do please keep visiting us on the website for announcements on these exciting developments. So through your amazing generosity we are able to fund at least three more research projects in this round.

There is also one more project which we would like to fund this year, but to do this we must ask you all to continue your fantastic efforts throughout the coming months. Together we can make a difference. We love seeing all your pictures of your events and it also means that we can continue to run our very successful schemes to help families throughout there CDH Journey.

Last but not least I would like to wish you all
**a Merry Christmas
and a Happy New Year.**

Brenda lane
Chair





2016

Butterfly Ball

This year our Charity Ball was held on the 22nd October in Scotland, in the beautiful city of Edinburgh and the theme was butterflies to celebrate our new charity butterfly mascots 'Hope' and 'Hero'.



We do our best to move this event around the country, so as to make it accessible to as many families as possible across the UK and this year we chose Scotland and the stunning Dalmahoy Hotel and country club to host our Butterfly Ball.

Sadly, things didn't get off to the best of starts when the company we engaged to manage the event let us down and sadly this resulted in poor ticket sales, but we dusted ourselves down, rallied around and managed to sell enough tickets so that the event could go ahead as planned and in the end a great night was had by all. The staff were very welcoming at the hotel and we enjoyed fantastic live music by The Royales and even learnt a few new moves from the Scottish Ceilidh session. It was also great to meet up with families new and old.

We unfortunately didn't manage to secure a main sponsor either, but some of our families sponsored tables and we had a Yorkshire based company Power & King Ltd take a business sponsorship. This was the first time we had used an event's management company due to our volunteers having work and family commitments this year. As no one organises our ball better than our committed volunteers, we have decided that due to the huge amount of time and workload required to organise this event we will be hosting the ball every other year rather the yearly.

We raised around £3000 on the night, which is less than usual, but considering the problems faced we are pleased. We would like to thank all of those who attended and supported this event, those who donated auction and raffle prizes and to our Committee for giving up their time to ensure that the event could go ahead.



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Research update

Thanks to your amazing efforts and continued support, our research fund has reached **£475,000!!!**



We put our first call out for research applications earlier this year via Sparks and we received a total of seven applications by the deadline. The applications were reviewed by external peer reviewers and finally by the Sparks medical advisory committee, who then provided CDH UK with a selection of fundable projects. We are pleased to say that we are able to fund all of the projects



deemed fundable by the peer review process and we are very excited by what these projects could mean for CDH patients and their families in the future. CDH UK has worked so hard to get to this point and we could not have done it without your support, so thank you again.

We hope to be able to give you full details on the grant awarded research projects very shortly. In the meantime please keep fundraising and supporting our Research fund.

Skydive world record attempt

June is CDH awareness month and this year we invited you to be a part of a world record attempt tandem skydive to raise funds and awareness for CDH. We filled all of our allocated places, but sadly the weather wasn't on our side and the record wasn't broken. This didn't really matter as we raised a massive amount of awareness for our cause and we would like to thank all of you that took part, or sponsored the brave divers. Also thanks to those that helped to organise the event and to skyline events and Do It For Charity for inviting us to participate. You can find lots of other events to take part in on the Do It For Charity website all year round. We hope you will join us in June 2017 for more CDH awareness events.

RAISING FUNDS FOR CDH UK!!



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CDH International Conference 2017

Every two years CDH UK attends the international CDH conference organised by the international CDH study group and the Euro CDH consortium. In 2017 it will be hosted by Professor Paul Losty and team at Alder Hey Children's Hospital in November and supported by CDH UK. We are very excited about this important event and hope to be able to share our Research Fund project updates during the two day conference and speak on important topics relating to CDH.

This is CDH UK at the last conference hosted by Toronto Sick Kids Hospital.



Get Togethers 2016!

We love our Get Togethers. It is so lovely that we can bring families together for support and friendship, which often turn into lifelong ones. It is also heart-warming for us to finally meet those we have supported through some tough times and to be able to use our meet ups to help us to improve support and help with study and research.

This year we held Get Togethers in Barnsley, South Yorkshire, hosted by our FLV Lyndsay Hudson, in Henley-Upon-Thames, Surrey, hosted by our Treasurer and FLV Kerrie Laird and in Lucan, Republic of Ireland hosted by Caroline Walsh. We would like to take this opportunity to thank all of our FLV's who have volunteered during 2017.

If you are interested in becoming a Family Liaison Volunteer in your county and are able to organise a Get Together in 2017, please email committee@cdhuk.org.uk



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CDH Stories

Cecilia

Cecilia's story... at the 20 week scan we was told Cecilia's heart wasn't in the right place and that they think it might be cysts in her lung. We then went to Nottingham to see a specialist which then resulted in me having a MRI as Cecilia was always in a difficult position so couldn't confirm if it was CDH. It was confirmed Cecilia had the rarer right sided CDH and her chances were at 50/50. We went back every week and was told her odds had dropped more. I had an amniocentesis to check to see if there were further problems but all came back normal.

At 26 weeks I was told it might be an option to end the pregnancy because the chances got slimmer and slimmer, I refused to give up. I was admitted to hospital on two separate occasions after with the concern of pre-eclampsia. But was sent home after a short stay. At 39+1 I went into Nottingham QMC hospital for a planned c-section due to being breech.

Cecilia was born on the 10.05.16 weighing 5lb 9oz. And the first hurdle was over, we was told she was making good signs she was up for the fight ahead. At 2 days old we was told the treatment she was on had been maxed out and the only option was ECMO, I was told Leicester team was on their way but they didn't think she would last long enough as she was quickly deteriorating. I sat and watched all her machine and her vitals drop. She arrested just as the ECMO team arrived. But she made it onto the machine. We then travelled to Leicester and watched our girl improve over the next 4 days.

At 6 days old Cecilia had her diaphragm repaired, a agonising 8 hours later she was out, the surgery was very complicated as the canulas in her neck came out and she lost a lot of blood which resulted in her arresting again. They had to leave her organs partly out of her body as they were too swollen to fit in the correct position. The next 24 hours were a whirlwind, Cecilias blood wasn't clotting around the wound so was still losing blood so was given medicine to help but unfortunately it clotted in the ECMO machine which then broke. We had an agonising 45 minute wait where Cecilia was losing blood and without her life support machine, awaiting for the surgeon in to replace the machine. Which in that time she arrested again but successfully made it back on. The next day they had another try and closing her hole, which was successful. Unfortunately the specialist had seen signs of fits so had to have a load of tests to check her brain activity whilst in Leicester.

On day 9 they attempted to get Cecilia of the ECMO machine and was successful. Day 10 we travelled back to Nottingham. Arriving on nitric, oxygen, sedation and ventilation.



Over the next 5 weeks Cecilia came on leaps and bounds. First the nitric went after 5 days being back, then sedation after 7, then from ventilation to CPAP machine then 5 days after that just oxygen nasal cannulas. Then the very next day nothing, no machines no medicines. We still had a MRI looming due to the fits and brain activity, which confirmed what we had been dreading, the loss of blood was too great for Cecilia and resulted in severe brain damage but wouldn't know till a year maybe 2 down the line at how badly that would effect her. The next day we got transferred to our local hospital in Lincoln where we spent a week to try and get Cecilia off NGT feeds and on to bottles. Due to having a bad cold not long after being home Cecilia was set back from bottle feeding and has never recovered. Although at 6 months old Cecilia is still being fed via the NG tube she is always a happy bonnie little baby! And hitting all her milestones nicely. We still have a long road ahead of us in regards to the brain damage but as you can see is always smiling and is doing amazing!!

This group has been there for me on the darkest days. CDH can make you feel very lonely. It tests you in ways I never thought was possible.

But there are amazing people in this group with extraordinary babies that are there to pull you through and help you when you need it most!

I wish everyone old and new the very best on your journeys and thank you for all the support!! Xxx



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Alex



I can clearly remember the day we got our diagnosis. My husband Tim, our daughter Elana, Nannie Annie and I, all went to our local hospital for the 20 week scan. Our biggest concern going in to that room was whether or not we should find out if it was pink or blue!

It started out so well. We did find out the gender, a little boy. We told Elana she would be having a baby brother. While the Sonographer carried on with the scan, we talked amongst ourselves at the excitement of having a little boy. I soon noticed the scan was taking – a while. The Sonographer said she was finding it difficult to get a good look at the heart. I volunteered a couple of star jumps and a big glass of water, but was told that wasn't the problem. She said she suspected a diaphragmatic hernia. Here I must confess, I was as guilty as many others. When the word hernia was mentioned, I thought "not a big problem, hernias are easy to fix". We were then led to a separate room to wait for a Doctor. They gave us information sheets on CDH, told us our baby had a 50% chance of survival, and that all further scans and care would be referred to Princess Anne Hospital in Southampton. They would be in touch soon to arrange a meeting.

Tim googled himself out that day, trying to find a way of fixing the problem as soon as possible. He soon discovered that we were in for a long wait to find out the outcome for our son. I just sat about numb for the evening. My Mum decided to stay to help us out, as I had been booked in for an amniocentesis the next day. As I read through the information sheets, I remembered there was an episode of 'One Born Every Minute', where the baby had passed away. I was out the evening it was originally on, so I recorded it. When I learnt what had happened, I couldn't bring myself to watch it. I did some research, and found that Kaiden had CDH. I went to bed crying, feeling totally disheartened.

The next week we had our first meeting in Southampton. We had the CDH diagnosis confirmed. Our little boy had stomach and bowel in his chest. We met the Surgeon, and had a tour around the NICU. Tim wanted to take in as much information as he could. We were told about the potential long term complications that can arise from CDH, such as hearing loss, lung disease, gastrointestinal issues, and mental and physical developmental delay. Then equally, we were told, he could have none of these problems.

Tim continued googling, and he came across CDH UK. He joined the support group for expectant parents, and eventually got me to join as well. To begin with, I didn't want to talk to anyone about the situation, but I soon realised we couldn't do this alone.



The next few months past in a blur. We had a lot of extra scans, and we got to meet the Consultant who would be looking after our son. I also signed up for the milk bank. I thought if I couldn't use it to help my son, then I wanted to do something to help other babies. I developed polyhydramnios, so I was given steroid injections. I was originally going to be induced at 39+4 weeks, but they decided to put it forward to 38+6 weeks, just to make sure everyone who needed to be around, was around.

On the morning of the induction, I went to the hospital with my friend Vikki for company. I had only been there for two hours when my little man's heart rate started to dip. I was taken to the labour ward for further monitoring. We called Tim at work, and he joined us. The induction was continued, but after another 24 hours it became apparent that my little man just couldn't handle it. His heart rate was dipping after each contraction, and it was failing to go back up again. I was taken to theatre, and at 4.30pm, Alexander was born.



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I didn't hear him cry, although Tim thinks he did. The anaesthetists very kindly took pictures of Alex for us after he had been intubated. He was wheeled past me before he was taken to NICU, but all I saw was the glint of a blue hat. We waited for the call from the NICU to tell us he had been stabilised. We got this at 7pm, so Tim was able to go down and see him. I was finally able to visit at 12.30am. I spent two hours at his bedside, just watching him and holding his hand, I would have spent all night, but the events of the last two days were catching up with me and I needed to sleep.

The next day we were unable to see Alex straight away as the room was closed off. Another family were saying their goodbyes to their little one. I just hoped we would never need to do this. Over the next few days, it was all about getting Alex stable, which we found was a bit of a challenge. He was on a lot of medication, he needed nitric oxide, and several ventilator modes were tried until we finally found one that agreed the best with Alex. To add to the complications, he had strep B, so was also fighting sepsis. Thankfully, antibiotics had been given to him from birth.



He was ready for his repair operation at 5 days old. After three and a half hours the operation was over. At our scans, we had been told that just stomach and bowel had herniated, however it turned out that the spleen and half the liver had also gone through, therefore Alex needed a patch. It was a long day. He needed x-rays, a long line fitted, more x-rays, a line refit, and even more x-rays. I finally got to my bed at 10.30pm, hardly having seen Alex that day. We were told the next 24 hours would be critical for him, with him taking a couple of steps back.

Alex however, astounded everyone in the NICU. The following 48 hours after his operation, he went from strength to strength, and actually took steps forward. There was even talk of being able to take him off the ventilator soon. The ventilator tube he had in was too small for his trachea. It needed to be changed, so they took a risk and tried him on high flow. He lasted about 15 minutes, before he was re-intubated. He just wasn't ready for it yet.

It wasn't long before we had our first big dip. Due to the paralysis from day one, Alex had struggled with retained fluids. When we called one evening for an update, the fluid was in and around his lungs, preventing them from expanding. Tim went and spent the night with him, just in case. Thankfully Alex picked himself up from that and started to move forward again.

A week after that first dip, we got a phone call at 6am from the hospital. Alex was struggling with his reflux. He had vomited and aspirated, which had caused a lung to collapse. When we got to the hospital, we discovered that Alex was requiring even more support, than when he was first born. We thought this was the end of the road for us. We stayed with him for as long as we could, and fully expected another phone call through the night.

The phone call never arrived, but for the next few days, when I went to see him he made no changes. After the fourth day, it was like looking at a different baby. Overnight, he had made enormous leaps forward. Now we had to wean his requirements, and get him off the ventilator as soon as possible.

At four weeks old, Tim and I got our first cuddles with him. I didn't want to put him down, but I had to, he was having a bronchoscopy to check for a floppy windpipe.

A date was planned to take him off the ventilator, but in true Alex style, he didn't want to wait, and two days earlier than planned, decided to self-extubate himself. We got another phone call to let us know, but we were reassured that he was doing well on bubble CPAP.

After 3 days he was moved onto high flow, and plans were put in place for us to be moved to our local hospital. It was bittersweet leaving Southampton. I was so glad to be closer to home, but sad that I had to leave behind the people and the routine that I was used to.

We expected to spend a while in our local NICU, but in three weeks, we managed to get Alex off high flow, onto low flow, and then on air. We did have many issues feeding, so we still needed the NG tube. We left the NICU on the 20th of December, just in time for his first Christmas.

It has been far from easy since leaving the NICU. Alex is now 9 months old, and we still continue to have steps forward and steps back. We have made progress with regards to his feeding. The most he has taken from a bottle in one sitting is 50 mls, so we do still need the tube to top him up. We began weaning him onto solids several months ago, it has been a slow start, but I see his progress daily.

After leaving the NICU on no additional oxygen, a month later he was readmitted with the flu. He needed oxygen again, but this time it was coming home with us. We successfully weaned him onto air many times at home, but respiratory infections set us back. A further three admissions to our local hospital have occurred since then, and it is during the fourth admission that I am writing Alex's story for you to read. I doubt this will be the last time we will see this place.

Despite the hard work, and frequent hospital stays, I know I am so very lucky to have him here with me today. He is such a loveable, friendly, and smiley young man, who I am very proud to have as my son.

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Betsy Susan Grace Corris

After having a baby boy in January 2015 I was pleased to find out I was expecting again in September 2015. The pregnancy was fairly straightforward up until my 20 week scan on January 13 2016 (unlucky for some!) and as I had been feeling my baby move a lot I was not overly worried about the anomaly scan.

On the day of the scan my partner Mark was not very well and worried about putting other pregnant women at risk so I went to the scan on my own. The sonographer was also pregnant so we were happily chatting away about our babies. After a while I realised that the scan was taking a long time and she told me she needed to go get another sonographer for a second opinion. I burst into tears (emotional pregnant lady!) and waited for them to come back into the room. When they did I could tell by the second lady's face that things were not good, she asked me if I was on my own, when I said yes my partner is not very well, she replied 'is he too ill to come in?' I knew then that something was very wrong and I phoned Mark and tried to explain, through tears, that all was not well with the baby.

The next day I had another scan with a consultant to confirm the diagnosis and talk about the condition and the future. I will always remember her saying to us that no matter what the scans look like or what survival percentage you get given, until your baby is born there is no way to tell how well the lungs will function.

We were referred to the Fetal Medicine unit at St Marys hospital under the care of Dr Iruloh and for the remainder of the pregnancy had extra scans to check on the progress of my baby. (I also did as much research as I could on CDH and googled it A LOT.... checking on the news sections to see if any new information/stories were available!).

Prior to my scan I had never heard of CDH, something I am quite surprised about now.

On 16 May at 5.46am Betsy Susan Grace Corris was born weighing 6lb 4ozs, she let out a tiny cry and looked so small and fragile. Betsy was worked on by a team in the corner of the delivery room and then whisked away to the NICU.

We were able to go see her properly just after 11am. We spoke with the consultant who told us she was on an oscillator and if things didn't improve then they would consider sending her for ECMO. Whilst pregnant I had researched all these types of ventilation/treatments /therapies so I had a fair idea that things were not great. Later that evening the consultant asked to speak to us to tell us that Betsy was on the maximum care that Manchester were able to offer and showing no signs of improvement. They had spoken to The ECMO team at Glenfield hospital in Leicester who was available to come pick Betsy up to put her on mobile ECMO. At about 4 am Mr Chris Harvey and the ECMO team arrived, they put her onto the mobile machine, and Mark and I were able to kiss her for the first time before she left. We were both so exhausted from having been awake for days that luckily my dad said he would drive us both there so we were able to get some sleep in the car.



Whilst pregnant CDH UK put me in touch with fellow expectant mothers on a Facebook group and I knew that one of the mums; Lauren had a little girl on ECMO IN Leicester at the same time. Whilst on our journey to Leicester Lauren messaged me to say Betsy had arrived safely and was in the bay next to her little girl Cecillia. It was extremely comforting to know she had got there safely and was being looked after.

Once we arrived at Glenfield the staff were brilliant, we saw Betsy who had two nurses caring for her for her first 24 hours on ECMO and then we were shown our room. The hospital put us up in family accommodation just down the corridor from Betsy so we were never too far away and did not have the worry of having to pay for hotel rooms.

After 5 days Betsy was stable enough to have surgery, (whilst still on ECMO) which went well (the surgeon told us she could come again!) however she was placed back on an oscillator the day after. I was quite concerned about this but reassured it was not a step back. Betsy was very poorly after surgery, she got an infection and struggled to come off ECMO. We had numerous doom chats with the consultants who told us they were very worried about her. Every morning The ward was always closed for 'ward round' and we used to dread getting a call from the nurses asking us to come for a talk with the consultant. I know now that if the consultants aren't asking you for 'a chat' then this is a good thing!

On 1 June 2016 after 4 previous failed attempts Betsy finally came off ECMO. We were so pleased but also so scared something would go wrong. We couldn't bring ourselves to tell anybody until she had been off it over 24 hours. The consultant told us he was pleasantly surprised she had come off as he didn't think she would. He described her as 'limping off' and told us not to get too complacent as if she had a wobble it would be a 'catastrophic' one. Mark and I spent the next 12 hours staring at the monitors and nervously awaiting the results of any blood gases.



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After coming off ECMO Betsy had issues with a chest drain and so remained in Leicester until she was stable enough to be flown back via air ambulance to Manchester on 10 June. Mark and I waved her off and my dad (John Platt) was able to go meet her at Platt fields in Manchester (st Marys does not have a heli pad) I remember calling st Marys on the drive back from Leicester to check she had arrived at the hospital safely and the receptionist At the NICU said 'yes don't worry she turned up!'

Betsy was put back in St Marys intensive care and after 11 days and one failed extubation with a collapsed lung she was successfully extubated from conventional ventilation and put onto BI pap. From bi pap, she went onto optiflow oxygen then slow flow and finally nasal cannula oxygen.

On 9 July she was transferred to our local hospital and continued to make progress eventually coming off all oxygen support. feeding was a big issue as she found it very hard to tolerate milk and also had to learn how to suck from a bottle, however on 3 August after just over 11 weeks in hospital, Betsy came home. It was only really the week prior to Betsy coming home that I really think she 'turned a corner' and felt she was ready to come home.

Betsy is our little miracle and although she still struggles with feeding and has been back in hospital once for monitoring with her cough, she really is a happy little girl.

The CDH journey really is a horrendous one, and everyone's is different. It was very hard not only seeing Betsy so poorly and wondering what each day would bring but also staying in Leicester away from our little boy for just over three weeks (luckily he was able to stay with his aunts and cousins so had a good time).



Life on an NICU is tough, after about 3 days I felt like I had been there three weeks! We met some lovely people and it's amazing how much other parents in the units and on the support groups helped get Mark and I through the tough times.

Betsy has been home nearly two months now, With a survival rate of 50% we realise we are very lucky to have Betsy still with us and for that I am so thankful.

A GRANDPARENTS CHRISTMAS WISH!



My Christmas wish would be if every CDH family got friends and family to donate just one £1 to CDH UK what an amazing amount of money and awareness that would be.



Since George was born he has had a quite few ops, the last one being this year!

The Fundoplication operation

(A Nissen's fundoplication is an operation used to treat gastro-oesophageal reflux. It uses the top of the stomach to strengthen the sphincter so it is less likely to allow food, drink or acid to travel back into the foodpipe). Although this operation doesn't suit everybody, it was a success for George (I also have everything crossed as I write this)

Before he had this his food intake was actually very poor, now he is thriving, has started nursery and is quite a lively little boy. I know his journey is ongoing but I really do see a light at the end of the tunnel

CDH is an amazing Charity which helps so many families in many different ways.



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Millie's CDH journey



I had a high risk pregnancy, due to a blood clotting disease, so was scanned every few weeks from 7 weeks to ensure both baby and I were OK. This meant by the time Millie was diagnosed at 34 weeks with CDH I had had 22 scans so was confused why it hadn't been picked up in earlier scans like the majority of CDH cases.

My 34 week Scan at Worthing hospital picked up a mass on my baby's left lung but at this stage they couldn't confirm what was actually wrong. We were taken into a bare consultation room with just two chairs, a table and a box of tissues and advised that we were being immediately referred to St Georges hospital 60 miles away for a scan where they would continue with our pregnancy care. We didn't at this stage even know what was wrong with her, understand why we couldn't stay locally for her care and felt distraught at this late issue being diagnosed. The following day we had a scan at St Georges hospital where she was diagnosed immediately with left sided CDH, something we had never even heard of. At this stage they explained they couldn't see her left lung at all on the scan so couldn't identify the level of damage that had been caused. What then followed was a whirlwind 4 weeks of 120 mile round trips every few days for tests and round table discussions with consultants, neonatal team, haematologists, surgeons etc all putting together a plan of delivery for Millie and myself as so many different people needed to be in theatre for us both. I don't even know how we got through each day as we were just existing. My birth plan went completely out the window!

It felt like our world was crashing around us and you also don't realise how much at the time the effect it has on your extended family going through your pain with you. What was supposed to be the happiest

time of our lives by looking forward to meeting our first baby in a few weeks was cruelly being taken away with the realistic fear that the odds of her surviving was drastically reduced. The bond my partner and I developed together at the worst time of our lives was truly unbreakable.

The specialists planned a caesarean for 38 weeks to give her the best chance of developing still in the womb and getting to a strong weight to fight once born. I had increased amniotic fluid levels so had to ensure I didn't go into labour early but it was hard to rest with so many hospital visits required leading up to the delivery. I went for my pre-op check the day before my planned caesarean and was swiftly admitted - without anything with me! My fiancé then had to sort arrangements for his kids who live with us and spent the next three days paying for a hotel until he could secure a place at the Ronald McDonald house in tooting. My Caesarian was then booked and then cancelled each day for a further 2 days due to no incubator available in intensive care for Millie. The stress of waiting in a ward, not knowing each day whether today was the day she was to be born and also not knowing the level of damage the CDH had caused and what the journey ahead was going to be for the rest of our lives took every ounce of energy from us.

When I arrived in theatre for my caesarean I couldn't believe how relaxed everyone involved made it for me. The neonatal nurses were even singing and dancing to the radio around her incubator waiting to take her immediately so it was reassuring to see how calm they were and my baby was to be in safe hands.

The decision was made for Millie to be paralysed and ventilated from birth so she wouldn't use her lungs to breath which could cause more damage. People don't understand the impact as a mum of not being able to hold your baby on your chest once delivered. They successfully ventilated her in less than 2 mins and took her away immediately so the first glimpse I had was her being wheeled passed me in her specialised incubator as she was taken to intensive care. All I could think of is my baby looked 'dead' as I laid in theatre waiting to be stitched up not knowing what was happening to her. Millie was a great weight at 7lb 5oz and full term at 38 weeks so I had to have faith that she had the best chance to fighting the CDH.



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I didn't get to see Millie that day as I couldn't get into a wheelchair after my surgery and there was no room for me to be taken down in my bed. Instead I laid in a ward full of 'normal' mums who had their babies next to them feeding and crying, the things you take for granted. If there is one thing I could change it would be for other mums with babies in neonatal to not have to be in a ward with other mums who had their babies as it's heartbreaking. To then top off my day the bounty lady came into the wards to sell their photography package but then swiftly exited my bay once she identified I didn't have my baby there and therefore she didn't have a sale! So insensitive!

The first 48 hours were crucial and I have never experienced such pain at looking at my baby girl swollen and paralysed from all of the drugs being pumped into her. I couldn't hold her but could put my hands through the incubator to touch her tiny hand which was black and blue already from the cannula. I Was scared to touch her through the incubator as was covered in so many wires, on life support and looked so fragile. I just Couldn't stop looking and staring at her, questioning why this had to happen to my baby girl.

We made sure our family travelled up immediately to meet Millie not knowing if she would make it but also as support to us. It was so hard dealing with the situation without friends and family close by and so far from home. The nurse looking after Millie kindly gave us a information to read for support which had the most overwhelming effect knowing there was this previously unknown support network available to us. I would sit by her incubator reading the bliss booklet digesting and understanding the journey ahead of us which made me feel so supported.

On The third day the surgeon phoned us first thing, explained Millie's gases/levels were unexpectedly in range and that they wanted to operate on her in the next hour! We had initially been informed to expect Millie to be in intensive care for a couple of weeks before any surgery so although we were apprehensive we knew this small window of opportunity needed to be taken. The scan had revealed that Millie's small bowel, large bowel and kidney had all been pushed through the hole in her diaphragm and were resting on her left lung. As a result her left lung is not full size and is only operating at 3/4 of its capacity and her heart was pushed across to the right hand side although this tends to move back itself rather than requiring further surgery.

I was discharged that day but unfortunately got readmitted after 2 hours in agony after they discovered I had a huge bleed in my stomach. I then required further surgery to remove the haematoma so ended up spending another week in high dependency myself and then had yet another bleed which painfully got infected! My poor partner was running between the two wards to see us both and bringing me down in the wheelchair to see my baby girl. One day he managed to walk 13 miles without even leaving the hospital grounds! I didn't manage to hold Millie for 8 days until she was transferred to the high dependency unit and I was well enough to have her placed on my lap. As a mother waiting for 8 days to hold your baby was heartbreaking and I must say I broke down in tears never knowing if I was ever going to have this moment.



My partner was able to stay on site at the Ronald McDonald house who offered amazing support both by putting a roof over his head to avoid the 120 mile round trip each day but also by offering to have a chat when he finally got back at 9pm mentally exhausted after another full on day. His children were also able to stay at weekends when they came to visit and extended family welcomed to use the kitchen facilities and garden just to have a break. They also had information on the wall of another CDH baby's story and it gave us so much hope reading of their recovery

Millie continued to amaze the doctors by recovering exceptionally well from her operation and was downgraded to high dependency 8 days after being born and then to special care one day after that where she improved over 5 days before being transferred to special care at our local hospital for 3 further days. We were not expecting to have even left St Georges hospital before Christmas so her recovery amazed us all. Apart from jaundice and a slight infection after her surgery she looked so healthy and like a 'normal' baby. We know we are so lucky For our CDH baby to recover this quickly is amazing and We know we still have a journey ahead of us until we understand the long term impacts of her left lung not forming/functioning properly but to look at Millie now you would never know the battle she's had to face so early on in her life. She will forever been known to all of our friends and family as our warrior princess.

Thanks,

LOUISA & Glenn

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Eppy Ana Bates



Me and my husband found out at 20 weeks scan our daughter had CDH. We stayed positive all the way through the pregnancy and when she was born. She was delivered by a planned c section as she was breech at Newcastle RVI. Unfortunately when she was born the ventilation never worked and she needed ECMO to help her so we got transferred to the Freeman hospital in Newcastle. She went onto the ECMO and had to be operated whilst on ECMO, which was a success. So we got transferred to our local hospital Northtees for recovery. Unfortunately our little princess became really ill her lungs collapsed with fluid on them she has one and a quarter lungs after the CDH operating. Then she had a 25minute cardiac arrest which the team in Northtees were amazing brought her back. She then got transferred back to the RVI and they diagnosed that our daughter had chylothorax. The chylothorax wasn't clearing which meant she needed to be operated on to seal where the chyle was entering. So we then got transferred back to the Freeman hospital for the operation. Whilst they went to operate they realised our daughter could not be operated on as they found a massive blood clot along her chest which was probably causing the chylothorax. She was on heparin for a while and it cleared the chyle. We then got sent back to the RVI for recovery she was such a little fighter. After 10 weeks she finally got to come home she now on tiny bit of oxygen to help make her lungs stronger and has a lung tube to help feed her. She struggles on bottles but she will get there. She also on injections for her blood clot. She is such a little fighter and inspires us loads always stay positive even when you have those days where you feel numb and don't know what's going to happen.



7 weeks after discharge Eppy was doing really well but she was not settling at all and not sleeping I took her to the doctors which they thought she had a chest infection. They referred us to Northtees hospital. Eppy was running with high temps and blood pressure was through the roof. Next day we were transferred to the RVI and back on the PICU ward. They noticed her fontanelle was protruding and her head circumference was bigger than a normal baby. They wanted to do a lumbar puncture to check to see if she had viral meningitis. When they done the lumbar puncture Eppy blood pressure and temperature went back to normal and they had released a lot of pressure from her brain. We were told Eppy has hydrocephalus which could have been caused from her cardiac arrest. Eppy was home after over a week in the RVI. We just needed to keep an eye on her head growth.

We thought she was doing well but Eppy's cries were quite tense when she cried she was tensing up all the time which we thought was mini seizure. After less than two weeks we were transferred back to North Tees. Eppy had all the symptoms again high temperature and blood pressure and her seizures were getting worse. North Tees got in touch with the RVI and they came down with the neonatal team as Eppy's head had filled up with fluid again. They done another lumbar puncture which helped take the pressure off her brain. That night she got worse again so the doctors gave her midazolam which relaxed her for a while. It took a few days but Eppy was slowly recovering and she was giving a stronger dose of omeprazole as she was getting a lot of reflux and they thought her spasms were coming from that. They treated her with antibiotics for a viral infection which seemed to have worked her head was a lot better too. She was ready to come home the fluid build up on her brain was caused by the viral infection. She wasn't having seizures but they were strong spasms which was making Eppy tense a lot.

Eppy came home after two weeks and she like a different child again full of smiles sleeping really well and we slowly weaning her off the oxygen. They have mentioned with the hydrocephalus she may need a shunt on her brain but fingers crossed she's fine now.

Thanks to all our family support and friends they all understand that Eppy can easily catch infections and they all understand. Now we have joined a few groups which has helped a lot with Eppy's physio and she's getting stronger every day.

Eppy Ana Bates was born 9th May 2016 and is a funny little character now.

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'Star with scar' sparks Emma's run to aid kids

CDH FUND RAISING MUM

By MATT JARRAM
newsdesk@nottinghampost.com

A MOTHER whose daughter was born with a life-threatening condition is competing in a 10km run to fund research and help other ill youngsters.

Emma Bradshaw, aged 38, of May Avenue, Wollaton, was hit with the news moments after giving birth to her eldest daughter Mina.

Mina was diagnosed with CDH, a condition where a hole has formed in the diaphragm and the intestines have crept into the lung cavity.

Mina had a successful operation aged just two days old and has made a full recovery.

Emma told the Post: "It was utterly devastating and horrifying. It is not a well-known condition. She was at the Queen's Medical Centre and they were absolutely brilliant. "We did not know what was in store for Mina until they operated. Twenty-four hours after being born she went for the operation. Every minute was like a day. You just want your baby in your arms and question why it happened."

Now a healthy and adorable three-year-old, Mina and her mum are determined to support other families dealing with condition by raising money for the CDH UK charity.

Emma will be competing in her 10km MoRun on Sunday, November 20, at Wollaton Park in Nottingham.

She will be running alongside her friends Nikki, Karen and Caroline, while Mina, her eight-month old baby sister Molly and dad, Ben, will be cheering their mum on from the sidelines.

Emma said: "We count our blessings every day for the help we had. We were able to take Mina home in less than three weeks.

"Lots of CDH babies are kept in hospital for months until they get to go home and around half don't survive - which is just heartbreaking. Thankfully Mina is OK now. She has a scar across her abdomen so we call her our 'star with a scar'.

"Our struggle has been more about my anxiety around her wellbeing. Mentally the whole episode has been really challenging and running has

been a brilliant release.

"I'm really passionate about raising money for CDH UK, but I also wanted to find a way to lose weight and get my endorphins going.

"MoRunning was the perfect way for me to achieve both goals at the same time!

"I don't plan to break any records, I just want to enjoy the process of getting fit, dressing up, having a laugh and raising money for a great cause. Knowing that we're running to help of lots of stars with scars will definitely keep us going!"

To support Emma's cause, please visit: uk.virginmoneygiving.com/team/Cdhuk10k

The Nottingham 5km and 10km MoRun will take place in Wollaton Park on November 20 at 10am. To find out more, visit www.mo-running.com/nottingham

"It was devastating. It is not a well known condition. She was at the QMC and they were absolutely brilliant

Emma Bradshaw



Emma Bradshaw with her daughter Mina, 3. Emma will be taking part in a charity 10km run. Inset, the Queen's Medical Centre, where Mina was born.

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Colour in the Christmas tree



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Christmas Word Search



elves
tree
chocolate
bells
bows
toys
lights
greetings
angel
winter
joy

reindeer
christmas
santa
gifts
holly
jesus
snowman
presents
snow

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t z o l e i a t g g n n e f o
k o q r y u l l s s i a j t e
n a m w o n s e a s w t r e e



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

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 charity page
uk.virginmoneygiving.com



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