



The CDH Magazine

EDITION 2 2021

Welcome from the Chairperson

It hardly seems any time at all since our last magazine edition and whilst it is great to see things getting back to normal in everyday life, I think we are all excited for Christmas this year and extremely hopeful that it will be a lot different from last year. We will be running our annual Snowflake appeal again this Christmas, along with some other Christmas fundraising and awareness initiatives so we hope that you will support us. Don't forget to head to our eBay shop for tree decorations and other festive goodies!

It has been another year of uncertainty for our families with regards to Covid-19, and by the time you are reading this we should have launched part 2 of our Covid and CDH survey. This year has brought additional concern for patients and families with the arrival of Winter viruses on top of Covid-19 and the potential of them being more of a nuisance than ever this year now schools and most other public spaces are back open. Please read our section in the Magazine on coping with these viruses. Access to our support resources has been high again this year and we are so grateful to our volunteers, supporters and donors who are helping to keep our services operating and running smoothly.

Fundraising and meetings have been challenging again this year and we made the decision to cancel plans for face to face Get Togethers again this year in the interest of our families and volunteers. Where possible we hosted and attended virtual on-line meetings, but we really hope that in 2022 we can meet up once again in person. Any events will be posted on our Social Media and Website so please keep visiting them for updates.

We have thankfully been able to continue with our research plans and work and we hope to be able to fund more research projects in 2022. We are really looking forward to collaborating on some new and exciting projects in the New Year and you can read more about this and our Research work in the Research hub section and on our website.



I would like to take this opportunity to thank all of you who have shared your experiences and stories for this edition of The CDH Magazine and to those of you who support our cause. I also want to give a special mention to our Trustees, Volunteers and Patrons who have all worked tirelessly to keep our wonderful charity operational, you really are a joy to work with and a pleasure to know.

For those of you going through a difficult time, you are in our thoughts and we are here for you anytime. CDH is often described as a rollercoaster ride with ups and downs, twists and turns and our aim is to support you and those who care for patients through this experience.

Have a very Happy and safe Christmas and New Year.

Bev x



CDH Research HUB

We have been busier than ever with our research collaborations and projects this year. We are extremely proud to have had some of our own research work published, which is the first ever patient led CDH research paper. This was done with the help of one of our Patron's Paolo De Coppi, Simon Eaton and Soichi Shibuya to whom we are very grateful for the support. The research focused on feeding issues and quality of life and the results we feel are really important for improving care in this area as we know a lot of families struggle with this aspect of raising a child with CDH.

We also saw the long-awaited results of the TOTAL trials which were two high quality clinical research trials undertaken to find out if the FETO procedure offered any benefits to severe left-sided isolated CDH and moderate isolated right-sided CDH. Our Research and Development Officer and current Chairperson Beverley Power was a member of the Data and Safety monitoring committee for the trials and was a co-author.



cdh UK **UCL** **NHS** Great Ormond Street Hospital for Children

Conclusion

- First patient-led survey
- High percentage of feeding problems
- Significant impact on patients' daily life
- Limited source of supporting information

CDH JOURNEY

The results

The results show that in Severe cases of Left sided Congenital Diaphragmatic Hernia FETO increases the chances of survival significantly. In fact, the survival rate more than doubled.

The results show that in moderate cases of Left sided Congenital Diaphragmatic Hernia even though an increase in survival rate was seen, the increase was only small. You can read all about this on our website research and news sections.

Another research project that we are extremely proud of is the development of a new guideline to improve pregnancy trials to pave the way for novel therapies for women and babies. This research was carried out by a team of international experts including CDH UK and the resulting grading system and terminology fills a vital gap in pregnancy research. You can read the full news article on our website.

We have funded further research projects and we have collaborated with some new research programs that we hope to update on throughout 2022. Please visit our Research hub on our website to follow and find out more.

Thank you for your support. Fundraising and generous donations that allow us to fund and participate in research.

CDH2022

We are looking forward to attending what is the main event for CDH UK in terms of research and networking in April 2022. This year it is being held in Glasgow and we can't wait to bring you updates after the event.

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Collaboration updates

Ernica

This year we attended the 5th annual ERNICA meeting as patient lead representative for CDH. The meeting took place in Lille, France.

A range of topics were presented and discussed, including the ERNICA registry, the CPMS, standards of care, animations for patients, parents and families, clinical exchanges, research and the future of ERNICA.

Here is a picture of the members who attended the meeting including our Chairperson and Research & Development officer Beverley Power (2nd row, 6th right).



DISCLAIMER:

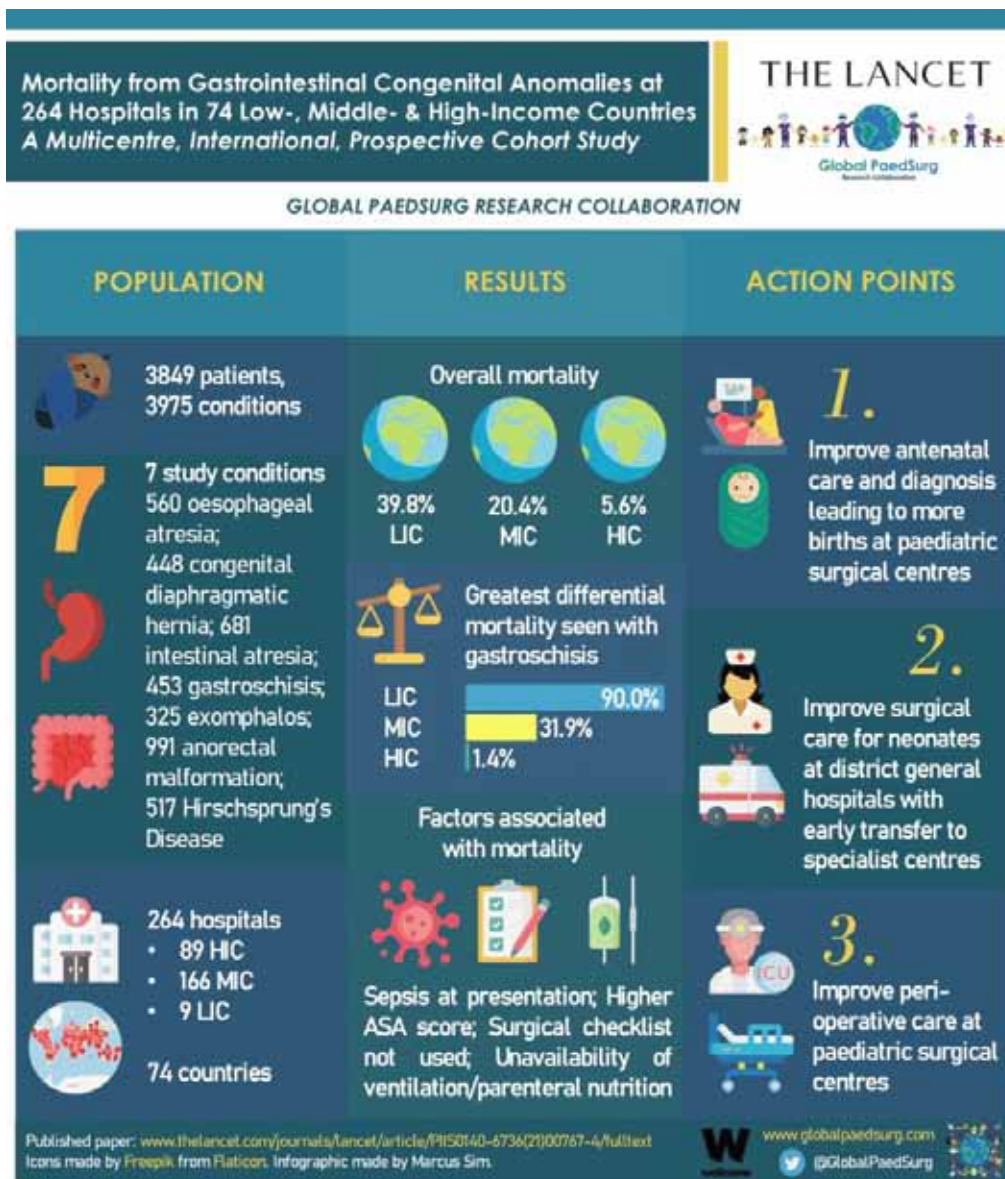
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Collaboration updates

Global PaedSurg

We also saw the first results from the Global PaedSurg project that we collaborate with. This was from a large multi-centre international prospect live cohort study of congenital anomalies in low and middle income countries and high income countries.

Here is an infographic of the results.



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Collaboration updates

NPEU and University of Oxford

We have also collaborated with the NPEU and University of Oxford with the CSOR project to help with patient information and to help engage patients into this exciting new study. You can find information on the poster below or by visiting YouTube and typing in Introduction to the CSOR study into the search box, where you can watch a short video.

What is a
successful treatment
for a child with
a surgical condition?

The University of Oxford is looking for

- Parents of children with a surgical condition
- Adults who have been treated for a surgical condition as a child
- Healthcare professionals regularly looking after children with surgical conditions

The information that is collected from this survey will be used to find ways to improve the care of children with surgical conditions.

To register for the survey, please click the link below or scan the QR code
bit.ly/3uKpnb6

www.npeu.ox.ac.uk/csor

NIHR National Institute for Health Research

NPEU SHEER

UNIVERSITY OF OXFORD

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Continuing to support CDH UK families



Lilly and her family were provided with a specialist pram funded by CDH.

"We used the pram to go to Legoland last week and today Lilly had an appointment at Great Ormond Street Hospital for an echo scan to check her pulmonary hypertension.

I took her in the pram on the train to the hospital and it's made it so much easier, as it's higher for me to push and helps my poor back - it's so sturdy".

Many thanks again.

Sally (Lilly's mother).



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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.

Baby Khan's story so far...

Baby Khan was diagnosed with left side CDH at 39 weeks on the 10th September 2021.

He was born 11 days later on the 21st September 2021 at Birmingham Women's Hospital and then transferred to Birmingham Children's Hospital for his repair surgery on 25th September at 4 days old, which went well.

He is now back at Birmingham Women's Hospital in NICU and he is recovering well. He is on 15ml of milk. It's a hard time for us as first time parents so please keep us in your thoughts.

Today 8th October 2021

Baby Khan is tolerating his feeds well.

Feeds will go up by 5ml every 12 days.

He is so much more relaxed and we just want to cuddle him.

Sometimes we get scared just in case we pull his lines out.



A big thank you to all the nurses, doctors, consultants and surgeons at both Birmingham Children's hospital (picu) and at Birmingham Women's Hospital (nicu) from baby Khan and mum and dad.

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Hunter's CDH story



Just like many pregnancy stories Hunter's started off perfectly.

He was growing nicely and I had my 2 routine scans and midwife appointments. We got to listen to his heart beat and nothing was a concern. It came to the end of my pregnancy (40 weeks) and we were told Hunter was smaller than they would like. It wasn't a massive concern to the midwife so she sent me for a scan.

The next day I had no real worries myself, I could still feel him moving in my tummy, we were just worried as to why he'd stopped growing. We had another scan the next day (40 weeks, 1 day) and they confirmed Hunter was definitely smaller than they thought he was going to be. They checked him on the scan and nothing other than him being small was brought to our attention, so I was booked in to be induced the following day. The next day came (40 weeks, 2 days) and we were so excited, we had to be at the Burton Hospital for 7am.

After a very long and traumatic 10+ hours, I was moved to the hospital's labour ward (as they wanted to keep a closer eye on the monitor due to inconsistencies with Hunter's heart rate) - we know now this is called bradycardia. I went into activate labour, with my partner holding one hand and mom holding the other.

We could feel the excitement in the room, but then it all changed - alarms went off and more people started to rush in.



After help from the doctors and one big push Hunter was born at 1:14am on the 1st December 2018 weighing 5lb 11oz. He let out a big scream and he was placed on my chest whilst my partner cut his umbilical cord and although it felt like he was there for hours it was less than 2 mins. He was lifted off me and placed onto a table. I could see them doing chest compressions and trying to give him oxygen, he was then rushed out of the room, we were told he would be fine and he would be back soon. My mom ran after him but was stopped at the doors at the NICU. After what felt like hours, 2 doctors walked in without Hunter and I just knew I could see the look of sympathy on their faces. Our worst nightmare was confirmed, Hunter had passed away after 41 minutes of fighting for his little life. All I wanted was to hold my baby, my sweet baby boy I had longed for, for so long.

We got to spend nearly a week with Hunter and I am so grateful we got to make some very precious memories with him. At this point we were still no closer to knowing why this had happened to us, he was perfect, how? what? why?

So many questions, yet we got no answers. After what seemed like forever (but was only 1 week) we had answers to some of our questions.

Hunter was born with a birth defect called Congenital Diaphragmatic Hernia (CDH).

This is when the diaphragm in the chest cavity doesn't form properly and in Hunter's case it was left hand side CDH. This is where the lower organs push up and develop inside the chest area, restricting the growth of the lungs. There is a 50/50 survival rate and 1 in every 2500 babies are born with it daily. The cause of the condition is still unknown.

Hunter's left lung had not grown and his heart had moved slightly due to the organs in his chest. He also had a bleed on the brain due to all the pressure, how could all this have happened and he still be so perfect and look so peaceful.

Our baby boy was laid to rest on the 21st December 20 days after he passed.



To our baby boy,

Mommy and daddy will look for you forever. We feel you're with us all the time and we are so incredibly proud of you and grateful you chose us to be your parents. You will never understand how much we wanted you, now you look at us from heaven and we look back from earth. I just know we will meet again, you're the reason I'm not scared anymore, our forever baby, Hunter Anthony Craig Bird. That's a name to be proud of.

We love you past the moon and beyond the stars.

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Freyah's CDH story



A reherniation experience

Freyah had her initial operation at 2 days old at John Radcliffe Hospital (Bristol Hospital was full) after her condition was picked up after birth at Gloucester.

At the start of this year, we noticed Freyah didn't have her usual energy levels. She had a cardiology appointment in March to monitor her pulmonary stenosis and we hoped we'd get some answers as we assumed it was connected to this and possibly asthma.

When we received the report letter from this appointment, we were informed that we were being referred to the surgeons for investigation after a suggestive X-ray. We knew then that she may have reherniated and an investigation appointment in May then led to a referral for an MRI that happened in late July.

During the period from the investigation appointment to the MRI Freyah became increasingly lethargic to the point where she wanted to be carried around most of the time.

After the MRI we had a call from the surgeon a week later to let us know that the MRI had shown that Freyah had reherniated, with her kidney and part of her bowel in the right side of her chest cavity.

We were told that she would be on an urgent waiting list and we were offered a cancellation a little over 2 weeks later for surgery.

She was down for surgery for nearly 5 hours as it was a finicky procedure with a lot of her internal organs adhering to each other. Her diaphragm was repaired with a patch. She was in Bristol hospital for nearly 2 weeks and as her weight was low and she found it hard to eat much she was sent home on an NG feeding plan which she is still on today.



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Theo's CDH story



Meet Theo...

LCDH with bowels up.



This was one of the first pictures of our little Theo.

We attended our routine 20 week scan but unfortunately the ultrasound couldn't be completed due to the baby's position in my tummy. They wanted to send any scanned images of the baby to fetal medicine.

As you can imagine we were very confused as we had not yet been told anything.

A few days later we visited my local hospital where I was re-scanned by a consultant and that's when the devastating news was given that our baby had a condition called CDH.

We were completely destroyed as you can imagine and we were given our options.

This baby deserved a chance to live and I certainly was not going to give up without a fight.



We had regular scans and monitoring and he gradually got better, but his lungs were small but were continuing to grow. I had extra water and was being monitored regularly.

The anxiety through my pregnancy was awful and very stressful. I was induced at St. Thomas' Hospital in London at 38 weeks & 6 days.

After a very intense labour of 10 hours, along with lots of scares along the way our beautiful baby Theo was born and he even gave us a cry.

From that moment on he had a rocky road ahead, but little did we know he was a lot stronger than we thought. He was so stable by day 2 that he had his repair surgery.

Day 4 he was extubated and now breathing on his own!

We were transferred back to our local hospital on day 8!

Theo was now only a feeding tube...

We went home on day 16! Amazing.

He was re-admitted to hospital a few weeks later with bilious vomiting and was in Evelina Children's Hospital in London for 9 days.

My baby has a Cow's Milk Protein Allergy (CMPA) and reflux, but we are now on top of it and he is thriving!

Theo is now 8 weeks old...
and a picture speaks a 1,000 words!

Believe in yourself, believe in your baby!

They are strong.
We have got this



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Livia's CDH story



At 23 weeks I found out my daughter had CDH. We were told she had a 27% chance of survival and that we should put ourselves forward for the FETO trial. After some research and speaking to the Surgeons at the hospital where our daughter would have her repair, we declined FETO and prayed we had done the right thing.



I had scans every 2 weeks from there on. At each scan her Lung to Head ratio improved and it more than doubled from initial diagnosis to 65% 1 week before she was born.

Livia was born via C-Section after a failed induction and was immediately whisked away and intubated and given everything she needed. I met her for the first time 4 hours later. She was on the oscillator ventilator when I first saw her and nothing could have prepared me for that. Each day she got stronger but there were MANY ups and downs. On day 12 she had her surgery at GOSH and she just made it all look so effortless.

She was finally discharged on day 51 but was having terrible reflux and bringing up most feeds so we were asked to return in 3 days for a weight check. We got settled at home and we're just finding our feet as new parents when it was time for the weight check. When they removed her clothes they noticed she was tugging at the ribs a bit so did a precautionary x-ray and they found she had reherniated, her patch had failed. 3 days she was at home, it was like a cruel joke.

So the surgeon recommended while he was doing the repair that they also carry out a nissens fundoplication as her reflux wouldn't have got any better she was already on max dose of the meds. So the surgery was done and we were home again about 10 days later.

Livia thrived after that, the nissen fundoplication really helped so much. She was at the top of growth charts because she couldn't physically vomit anymore.

At 18 months old Livia was having a barium swallow study to see if she still had silent reflux despite the nissen. During this they told us she had reherniated yet again. We just couldn't believe it, mainly because she had zero symptoms and was as lively as any child that age. Her surgeon decided that we should wait to do the repair this time as she wasn't suffering at all. I remember thinking she is a ticking time bomb and this could go so badly, but it didn't. She continued to thrive. So over a year later when she was 2 and a half she had her third repair. This time a latissimus dorsi flap repair which uses the latissimus dorsi muscle from her back. This was because the patch kept failing.

We are now almost 2 years post-surgery, she has only had 1 xray since and that was all okay. Hoping for another soon because when I didn't know twice before that she had reherniated I find it very difficult to accept everything is okay just because she seems okay.

Livia still has a gastrostomy button, we have never needed it for feeds - just for venting her air as she cannot burp at all since the nissen. She is starting Reception in September this year and I was a bag of nerves but also I cry every time I think of that little baby on day 1 and what I would have given at that time to know in 4 years' time she would be starting school.



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Daisy's CDH story



In early 2006, we were pregnant with our third child and we were all excited by another member of the family. The initial 12 weeks scan went without any issues and we looked forward to the months ahead.

We received the appointment for the 20 weeks scan and we looked forward to seeing the images of the next member of our family. However, during the scan the sonographer said that she needed a second opinion, but would not elaborate further and she left to find a colleague. After reviewing the scans we were taken to a doctor's office, where we were informed that an abnormality appeared on the scan and asked that we attend St. Mary's Hospital in Manchester the following day for a more detailed scan.

The lack of clarity and information was concerning and we spent that night worrying about what the future held for us, our unborn baby and family.



We attended St. Mary's Hospital the following day for a more detailed scan and a consultation with a specialist, we were informed that the scan showed that our baby had developed a left sided CDH and a hole in its heart. The seriousness of the condition was explained to us and we were told that our unborn baby's chances of survival were 40% and if it did survive, it was likely that sports or physical activity would be a struggle due to the underdeveloped lungs. The consultant recommend an amniocentesis to check for any genetic or chromosomal conditions that "may not be compatible with life". It was an upsetting and worrying time, plus it made the procedure all the more scary, but it went well and thankfully there were no other medical issues.

It was at this point that that we decided to find out the baby's sex. It was a girl. We were all delighted, except our son Joe, who was 6 at the time. He was very unhappy and wanted a brother.

My pregnancy progressed and eventually, as my expected due date approached, the team at St. Mary's Hospital explained that due to the CDH condition a planned C-section would offer our daughter the best chance of survival. The team would be ready to help our daughter through those first few hours and days, which was a critical period.

At 12.33pm on Monday the 2nd of October Daisy was born weighing a healthy 6lb 13oz. We heard 3 small cries and my husband was allowed a few seconds to see her and then she was rushed to the neo-natal unit to be ventilated. I met Daisy the following day and I remember thinking how beautiful, strong and brave she was.



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Daisy's CDH story (continued)



After 5 days on a ventilator, the neo-natal team were satisfied that Daisy was strong and stable enough to undergo the surgery that, hopefully, would allow her to survive. In our mind we were reminded of the earlier chances of survival we had been told about, which was less than 50%, but we remained positive that the surgery would be a success.

On Friday 6th October Daisy was taken to theatre for the operation and after several agonising hours we were told that the surgery had been successful and a patch had been fitted to repair the hernia. However, she remained in a critical condition, on a ventilator and fed by tube. I expressed milk for her, which was important to me as this felt like the only thing that I could do for her at the time.

Over the course of the next week Daisy became stronger and removed from the ventilator, which meant that we could hold her for the first time, which was very special. Despite continued improvement, Daisy developed a blood clot due to the "long" line in her foot that was used to administer medicine and so she was given anti-coagulants for the next 6 weeks.

Over the next weeks, Daisy was moved from neo-natal intensive care unit to the special care ward, which was a big step in her recovery. It also meant that her siblings and other family members could visit her in hospital and on a couple of occasions, she was able to spend an afternoon in her own home.

After 7 weeks and 3 days Daisy was able to come home on a permanent basis, which whilst exciting also made us slightly nervous, but we soon found a routine and Daisy was developing well.

Daisy regularly attended Manchester Children's Hospital, which replaced the demolished St. Mary's Hospital, for routine check-ups until she was discharged, aged 7 years. Despite having developed mild seasonal asthma, Daisy was a very active child at primary school. She was a key member of the tag rugby team, played netball and loved horse riding amongst other activities like climbing trees.

Fast forward to 2020 and by now Daisy is 14 years old and towards the end of that year, she complained of the odd pain in her side that she described as a "stitch". We didn't think a great deal of because it came and went, but in March 2021 Daisy was still experiencing the "stitches" and so we decided to make an appointment with her GP.



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Daisy's CDH story (continued)



The GP examined Daisy and didn't find anything unusual, but as a precaution sent her for an X-ray and said we would be notified if there were any issues. We didn't hear anything from the GP and we assumed there was nothing that appeared on the X-ray. However, 4.45pm on Wednesday 7 April we received a call from Manchester Children's Hospital informing us that something had shown up on the X-ray and that Daisy needed to come to the hospital immediately for a CT Scan and that she would need an overnight bag, just in case.

The CT Scan confirmed what the consultants had thought. Daisy had developed another left sided CDH and that the large bowel had twisted through the new hernia.

It was surprising, because Daisy had been to netball training on the Tuesday evening and was horse riding on the morning we received the call from the hospital.

Daisy was being very brave, but things were moving very quickly. The consultant told me that she would require immediate surgery and this may involve removal of part of the large bowel, which I could not bring myself to tell Daisy. She was taken down to the operating theatre for surgery at 12.15pm and we expected to see her again a couple of hours later. However, 4 hours had gone by and I had not heard any news. In the end, the surgery took 6 hours. The consultant told me that children with this condition can have a lot of dense scar tissue, which can lengthen the surgery time.



The operation was a success again and there was no need to remove part of the large bowel either, which was great news. Daisy was very sore for days afterwards and was on continuous morphine for the first couple of days, but she encouraged to get up and walk about to help reduce the risk of a blood clot and was discharged from hospital after 4 days.

Daisy did suffer with some anxiety after the surgery as every pain she had, she would worry the new patch had not worked and she would need further surgery. Within 6 weeks Daisy was back on a horse and is playing netball 3 or 4 times a week.

Whilst Daisy's progress will be monitored and reviewed every 6 months for the next couple of years by the hospital, we are lucky she has recovered so well and that she can still enjoy her favourite sports, which for someone we were told was unlikely to lead a sporting lifestyle before she was born, is satisfying to see.

We hope that Daisy's story will help raise awareness of the condition and provides an early warning sign to parents whose children have CDH and are growing up.

Daisy Clarke, Nicola and Tony.

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Rachel's CDH story



'Transition of care'



Hi everyone,

Let me introduce myself first. I'm Rachel From Ayrshire, in Scotland and I was born with left sided Congenital Diaphragmatic Hernia. I am now 31 years Old. My CDH journey has been a long one and has sometimes been rather complex. Some may already know about the complications of CDH and its variety of possible ongoing issues, but I wanted to share my personal experience.

I had a great standard of care within the paediatric services, but it really changed and took a different turn when I turned 18 and was ready to move over to adult service. This is what is often referred to as 'Transition of care'. Initially all went smoothly, appointments between my paediatric consultant and new adult consultant went well and I was transferred to adult service fully by 19 years old. Then low and behold after one face to face appointment without my paediatric consultant I was discharged because I was well....,

fast forward 6 month and my health had spiralled downhill with constant bouts of sickness, constant chest infections, both of which resulted in hospital stays. At the time this was pretty frightening when we had been used to the safety net of paediatric services within my local hospital. Soon as I was well again and they then just let me home and did not really investigate the full issuemy Diaphragm was intact with no reherniation; so why would they keep me in I suppose.

Everything eventually peaked in the summer of 2011 when I was admitted to hospital extremely ill and underweight. We were, as a whole family, at our wits end as to what was going on. This resulted in a 4 month stay in hospital.

A few things happened during my stay that resulted in being put in touch with a respiratory consultant, who was thankfully on the ball and just happened to be on call that weekend. They realised that due to my CDH and knowing that I would have some sort of issue mild or severe and contacted my paediatric consultant to get a full background. Hooray we thought...now onto the next hurdle. That problem had started to be resolved and managed and the sickness had died down, so again I was sent home with no follow-up for the sickness issue but regular follow ups with respiratory....so you guessed, yes it started to spiral again. My GP surgery was always amazing during this, but there was only so much they and a



Me as a baby with my Mum.

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Rachel's CDH story (continued)

dietician could do between them. It also didn't help during a few admissions where I had been accused of having an eating disorder, but then just one time a consultant happened to take a good look at my notes after being pestered by a nurse and realised; wait a minute there is more to this. This nurse who'd taken an interest ...on the complete off chance led to a turning point 2 years later in 2013. It literally just happened because someone wanted to know more and a very pushy nurse who had dealt with me on countless occasions and knew this wasn't right and had therefore investigated CDH online. I also received support from CDH UK and they suggested things to mention to the Doctors, one of which turned out to be what I was eventually diagnosed with.

It took a few months after the first off chance meet, but we got there, we got a plan and we got someone who was willing to help and figure things out. I was diagnosed with gastroparesis at this point, which explained all the sickness, the nausea and the weight loss.

My point is there may have been the initial transition that went well, but this quickly changed and there was absolutely no knowledge base or very little about Congenital Diaphragmatic Hernia. To them it was fixed, so there wasn't any other issue, but if in the first incident they had investigated properly or had some prior knowledge of Congenital conditions they may have realised that there was a bigger picture.

I am thankful for now that I am well and have a healthy 6 year old daughter too! (another story for our next CDH UK Magazine). I still have some ongoing issues that I know I will always have, but I think that there needs to be better Transition and better focus in the adult sector. If I can help strive for consistency building on the already great progress being made by CDH UK, this may help others in the same situation I was in or will help to avoid it in the first place. I will continue to share my story and with the support of CDH UK.



Me and my 6 year old daughter.

CDH is a journey that doesn't stop at the repair and I will say that always.

Best wishes to you all

Rachel Richmond
(Committee Member and Patient Ambassador)

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A chat with Sarah Jones

our Fundraising Administrator



Q What does your role involve?

A I am currently the Fundraising Admin and my role involves answering emails and chatting with people who want to fundraise for us, I give them advice on things to do and how to go about doing it, I issue fundraising packs ready for in aid of events and also support them through their fundraising journey!!



Q How long have you volunteered for CDH UK?

A I have volunteered for CDH UK for 3 years now. I used to just do the certificates but then my role progressed!

Q How did you get involved with the charity?

A I got involved with CDH UK because when I was pregnant with my 3rd son, we were given our diagnosis. We did a fundraiser at our local church and raised £700. It was then that I decided that no matter what the outcome was with Matthew, I wanted to help raise more money to further support others in our position and to help find out why this happens.

Q What do you like best about your role?

A I love meeting new people and chatting! I have made some fantastic friends through doing this role.

Q What advice would you give to others who are thinking of volunteering?

A Do it!! Even if it's just a little bit once every few months, you can really make a difference to the charity. We had no idea what CDH was until we had Matthew, nor did any of my friends. Now, in just our small community, lots of people know about the condition & what the outcomes can be.

Q What advice do you have for anyone wanting to fundraise for CDH UK?

A Fundraising is fun!! Whatever you choose to do, be it a coffee morning, a sponsored walk or run or even a skydive, you're going to have a laugh & do something amazing!!

Q What are quick and easy ways to fundraise for CDH UK?

The easiest ways to fundraise would probably be to run or walk a particular distance or a cake sale. We had a lovely lady recently who ran 3K every day throughout October & she did brilliantly!! Or if you want to set yourself a higher bar, organising a family fun day is always challenging!

Q How does the charity thank people for fundraising for the charity?

A We always try to thank everybody that has been involved in raising funds for us. I issue a certificate/s to recognise the fantastic achievements that people do and depending on totals raised or the amount of work put in for example, we will issue a medal or gold badge. We always like to celebrate people on our Facebook page too, no matter how big an amount raised.

Q Name three things you have learnt about CDH UK since joining the team?

A 3 things that I have learnt since joining would be that friendship can certainly be undervalued. Since our diagnosis right up to now, the group of lovely people that I can call good friends is really special to me. People can achieve such great things, even when bad things happen & really pull together to support a great cause.

And if it wasn't for the amazing fundraisers that we've had & currently have, this charity wouldn't be able to help half as many families that it does now. Everyone involved in CDH UK, has a link to the condition and that makes us one big family.

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Our Fundraising CDHeroes!

We are so grateful to each and every one of you who donate and fundraise for CDH UK. Every penny raised makes a difference. It doesn't matter how much you raise, the fact that you helped to support our work is what matters. The more people that support us, the more we raise. Of course some events are truly inspiring and go above and beyond any expectations and these can include difficult personal challenges and large organised events that raise phenomenal amounts of awareness and funds and we want to celebrate these exceptional efforts.

We have had a really difficult start to 2021 for a few reasons and not least because everyone has been affected by the Covid pandemic, which has resulted in financial strains for everyone and increase in demand for our resources and schemes. This means that our donors and fundraisers are even more important to us as we head towards 2022.

We also want to pay tribute to Mark Hemstedt who has made a real impact on support by his generous donations to CDH UK in memory of Baby JJ (CDH). Mark sadly passed away suddenly and our love and thoughts are with his family and friends. His legacy lives on in his kindness and generosity.

3K a Day in October

Tracy McCubbin set herself a real personal challenge of running 3K every day during October to raise awareness and funds for CDH UK and she smashed it!

She was inspired by a close family friend whose son was born with CDH and has undergone many surgeries in his short life under the care of Glasgow Children's Hospital.



Tracy, who raised over £600 said 'So glad I've been able to do something to help this amazing charity!' and commented 'you have helped this family in so many ways'

We say you are terrific Tracy and a true CDHero! Thank you to Tracy and everyone who supported her. **P.S Love the CDHero outfit.**



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Our Fundraising CDHeroes!

CDH Family Fun Day

Hollie and friends organised a family day at a local community hall to raise awareness and funds for CDH. It was an amazing day and everyone seemed to really enjoy it. They managed to raise **£976.34 on the day!**

The fundraiser was inspired by Charley and Georgia who attended in their CDH Teach Shirts. These can be purchased through our eBay store.



Well done Hollie and friends and of course Charley and Georgia!

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Our Fundraising CDHeroes!

A Night to Remember!

Deborah Thompson and friends organised a party night in aid of CDH UK and what a night it was! Live singing, auction, raffles and a disco to entertain their 200 guests!



Our Committee member and patient ambassador Rachel Richmond attended the event to speak about CDH and the charity and said 'Wow what a well organised event!'

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Our Fundraising CDHeroes!

The event was inspired and named after Baby Micah McEwan, who was born with CDH.



The event has so far raised over £10,000 and has a goal of £20,000 and we hope to have a final figure raised soon. This really is an absolutely amazing effort and everyone involved in organising it should be very proud! We would also like to thank the guests who attended and helped to raise this phenomenal amount of money for CDH UK.

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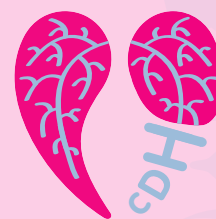
Awareness 2021

CDH UK has it's main CDH Awareness campaign in June, with June 28th as it's official awareness day. Thank you so much for joining in with awareness activities and making it another success this year. Please follow our Social media accounts and website for news on our 2022 awareness campaign.

This year we were so excited to see so many of you requesting landmark light ups for CDH awareness and we are going to try and add more landmark light ups in June 2022. If you would like to get involved please email awareness@cdhuk.org.uk and we will send you further details of how to go about getting a local landmark lit up. Thank you to the following landmarks for helping to raise awareness:

BLACKPOOL TOWER
ST ANDREWS HOUSE, EDINBURGH
VICTORIA QUAY, EDINBURGH
SMEATON'S TOWER, PLYMOUTH
FALKIRK WHEEL
GUILDHALL, WALES
SOUTHWATER ONE, TELFORD
NEWRY TOWN HALL, NORTHERN IRELAND

Here are some pictures from June 28th 2021



Madison's Movement



We decided last year to continue Madison's kindness with an initiative called "Madison's Movement" to help raise further awareness on CDH Awareness Day on 28th June. Madison was an avid supporter of CDH UK and our work and helped to raise awareness at every opportunity. She sadly passed away at just 17 of a complication of CDH and we decided to pay tribute to Madison each year on awareness day. This year the movement asked you to support **Colours 4 CDH** by posting pink & blue hearts on your social media posts or wearing pink & blue to school or work. Thank you to all who joined in!

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Impact Statement

Our impact past and future

2021 was a great year for achievements and our main focus was creating new good quality information leaflets to add to our existing 'Introduction to CDH' booklet and adding further resources for patients and clinicians. In 2020 we presented the first draft of The CDH patient journey at our Great Get Together and in 2021 we further developed this. We are excited to share this with you all in the very near future.

We also created a new section on our website relating to Transition of Care, which you kind find under the section 'Need Help?'

We hope you will continue to support with your generous donations and fundraising.



Our Vision Our Mission: Through information, awareness and research, CDH UK is supporting patients, families and healthcare professionals and helping to improve outcomes for those affected by Congenital Diaphragmatic Hernia & Eventration of the diaphragm.

27

VOLUNTEERS

From Management Committee members to support pack co-ordinators, supportline handlers to fundraising administrators, Family Liaison Volunteers to Bereavement Buddies, Awareness Merchandise admins to Trustees and more! They gave their spare time, skills and love to help our cause!



1st

Research Publication

We published the first patient led research paper titled 'Long-term feeding issue and its impact on the daily life of congenital diaphragmatic hernia survivors: results of the first patient-led survey', to help improve feeding support and outcomes.



MORE THAN

£35,000



granted to supporting patients and families. This helped with the additional costs of having a baby/child in hospital or with additional needs. It included helping families to have a much deserved break away.

OVER

£600,000

DONATED TO RESEARCH

We grew our Research fund even more during 2020 to add to our already amazing total above! We hope to grow this further in 2021 and contribute even more!



3328

HOURS

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



100'S

SUPPORT PACKS, INFORMATION BOOKLETS & MEMORY BOXES

Distributed to families comprising of newly diagnosed parents, bereaved parents, School starters, Healthcare providers



What will you do to support us?

How will you help to improve outcomes?



Volunteer



Partners



Fundraise

DONATE NOW

FREEPHONE SUPPORTLINE

0800 731 6991

email: support@cdhuk.org.uk

SOURCES

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

CREATED BY

CDH UK - The congenital Diaphragmatic Hernia Charity



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2021 Snowflake Appeal

We are excited to see our 2021 Snowflake Appeal launch on 1st December. The appeal has run for a couple of years now and is designed to encourage extra donations for our Research Fund during the festive period when giving is all around us.

This year we have decided not to bring out a new piece of Christmas merchandise as we still have previous year's items to sell and we want to think about reducing our carbon footprint and looking for things that are more environmentally friendly in the future. So please visit our eBay store and take a look at some of the lovely Christmas items we already have in stock.

We have our first ever online **CDH Christmas Cracker Quiz** at 8pm on 17th December and so please head over to www.virtualquiz.com and register to play in this quiz where you could win a cash prize whilst raising funds for CDH UK.

Why not make a Christmas Party night of it and invite family and friends to play together as individuals or as a team!



Don't forget the virtual Christmas balloon race where you can win

- 1st prize Christmas Hamper,
- 2nd prize Snowglobe or
- 3rd prize Metal snowflake tree decoration!

Good luck and don't forget that the more people get involved the better!



Colouring in



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CDH UK

Christmas films

Word Search

- nativity
- miracle on 34th street
- white christmas
- love actually
- deck the halls
- last christmas
- arthur christmas
- the snowman
- holiday inn
- the grinch
- its a wonderful life
- scrooge
- home alone
- jingle all the way
- elf
- noelle
- the polar express

n t r v j i n g l e a l l t h e w a y l s s
 f s x e a e l l e o n s m c r u e a d c r a
 l a s a l m o n d s v a s o n d a l t o n m
 h p i p n j n e a a g e w a y i p e t i g t
 w h i t e c h r i s t m a s s u e a r x e s
 n c r e a d c r u m b s m c r r e w d c f i
 n n a t i v i t y m b s m c t u e t d c i r
 l i s h l m o n d s m a s s n u h l m o l h
 h r i e n n i g i n g e h i g e a n t i l c
 e g o s a n x s u u e t i x p u p l r x u r
 e e u n r i y n l t 4 g d o n l l r l y f u
 g h r o a y c r u 3 b s l c r u e a d y r h
 o t u w i a u t n e r a h u t t s i b u e t
 o y o m s d r o n g r s r r a n n s o r d r
 r s l a i i e m t e e u c b m t r i d b n a
 c d f n f l e i x e e g d e n o l a e m o h
 s y i l c o d p a r b a e d n a l s y d w e
 m w j a e h r e a s a m t s i r h c t s a l
 e f r p a e x s u d e c k t h e h a l l s i
 n i r e s d c r u m b s m c r u e a d c t m
 m d f s n e s i w e e g d s i w e n e s i d

Useful websites

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

Asthma UK
www.asthma.org.uk

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

Bounty - Support for new parents
www.bounty.com

British Heart Foundation
www.bhf.org.uk

CDH UK is a member of Rare Disease UK
www.raredisease.org.uk

CDH UK webshop
www.giveasyoulive.com

Child Bereavement UK
www.childbereavement.org.uk

Contact
www.contact.org.uk

Ebay for charity CDH page
www.charity.ebay.co.uk/CDH-UK/125342

Medical Research Articles
www.bmj.com

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

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

Enthuse
www.cdhluk/enthuse.com/profile



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 Hernia Charity

