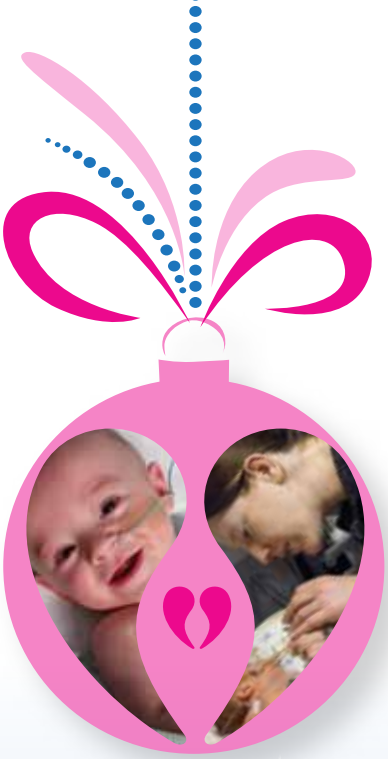


CDH UK NEWSLETTER 2017

cdhUK The Congenital Diaphragmatic Hernia Charity

Welcome to our Christmas 2017 newsletter!

2017 has been very busy for CDH UK, but we are thrilled with all our achievements again this year. From our Get Togethers to International conferences and research projects to supporting families through diagnosis and pregnancy or the grief of the loss of a child, to the highs of those who get to go home, CDH UK tries to help as many families and professionals as we can, in whatever way we can.

So I would like to thank you all for supporting the work that we do and will continue to do with your help in 2018 .

I would also like to thank our Trustees, Committee, Patrons and volunteers who give up so much of their time to help in many different ways through-out the year.

I do hope that you can all relax over the Christmas break and that the new year is kind to you all.

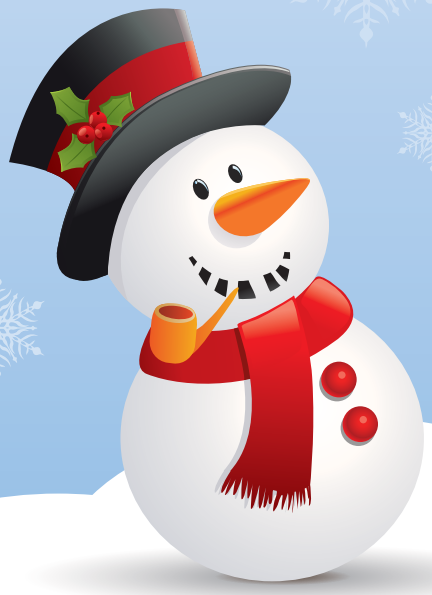
Merry Christmas and a Happy New Year
From the team.

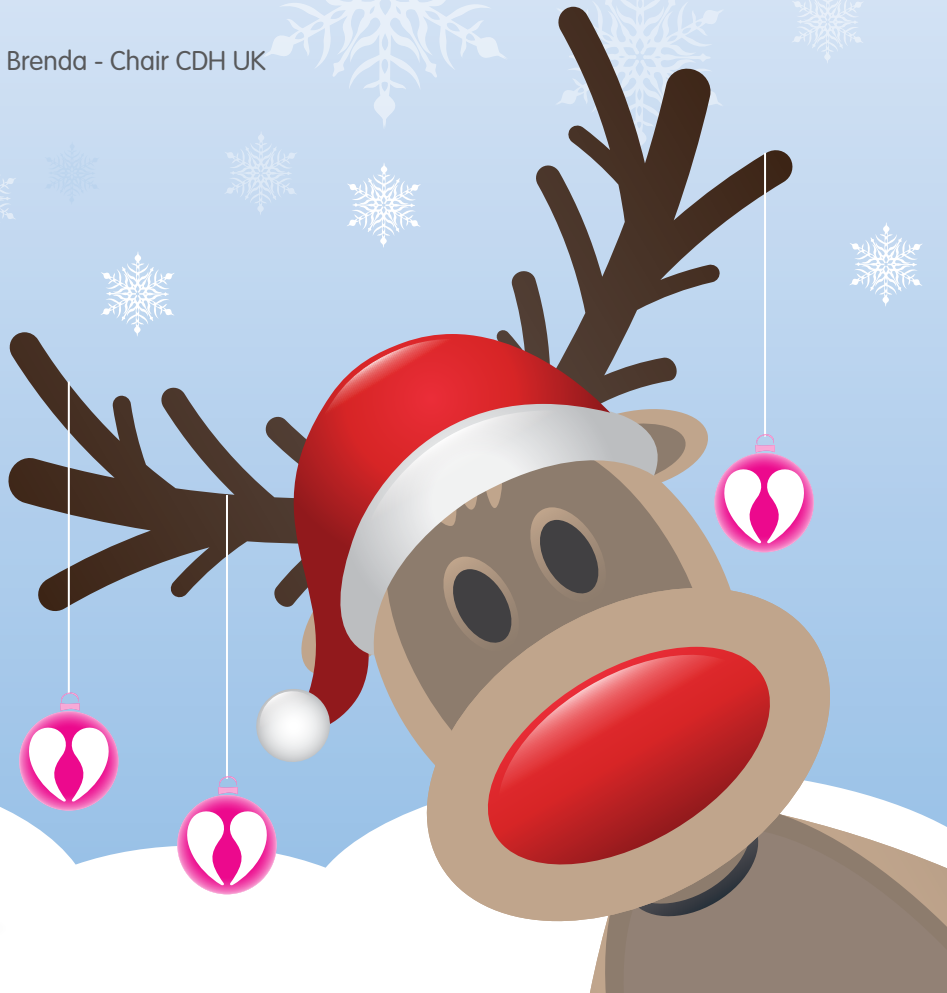
Brenda - Chair CDH UK

A warm welcome to the new 21-page bumper edition of the CDH newsletter! Our latest issue is packed with a mix of informative features, event news, fundraising news and, of course, some amazing CDH stories shared by parents across the UK. As usual, we've included something for the kids with a Christmas word search and colour-in picture of Santa to print out and enjoy over the festive season.

On behalf of the CDH charity I'd like to thank you all for your continued support and to wish all our readers a Merry Christmas and a Healthy New Year!

Tony Smith,
Editor.





Research feature

CDH UK funds vital research into CDH.

CDH UK is proud to have donated nearly £500,000 to four exciting research projects during 2017. This has been made possible by your generous support and donations and the help of our partner Sparks and GOSHCC who action our research call outs and peer review and manage all of the applications and projects on our behalf. We hope that you will continue to support our research fund during 2018 to allow us to fund even more vital research for CDH patients. We have some exciting fundraising opportunities coming up so please keep following our social media pages and our website for details.

The four projects and their Principal Investigator that we awarded research grants to are as follows:

1) Building a functional muscle to repair congenital diaphragmatic hernia - Professor Paolo De Coppi - UCL institute of Child Health, London.

Current situation:

Congenital diaphragmatic hernia remains a challenging conditions and children with good lungs sometime have problems related to the repair of the muscular defect. In particular large defects are repaired using artificial matrices which relapsed, get infected or can cause spine or chest deformities.

How this research will help:

We are proposing here to design an innovative treatment based on our extensive research and preliminary clinical experience on engineering functional organs and tissues in the laboratory. Similarly to what we have previously done for the trachea, we are planning to built here a functional muscle patch using patient's own stem cells. The stem cells, collected before the baby is even born, will be transformed into functional muscle and seed them on a diaphragm derived from animals which will have its cells strip out. This functional muscle will not be rejected by the baby and will offer a better repair to what is available at the moment.

2) Long term health and health service use in children and adults with congenital diaphragmatic hernia.- Dr Neil Patel - Royal Hospital for Children - Glasgow

Current situation:

Congenital diaphragmatic hernia (CDH) affects approximately 250 newborn babies each year in the UK. With advances in newborn intensive care most affected babies survive to go home in the first months of life. However, many may have on-going health problems in childhood and beyond.

We do not fully understand the health issues that CDH patients may have throughout their life. For example, which conditions they are prone to, how often they need treatment, and how this may affect other aspects of life such as their education. This makes it difficult to plan the best services for patients.

How this research will help:

This research will help us to understand the long-term effects of CDH on individual's health and education. We will study a group of 400 CDH patients to learn which health services they use, conditions they have been affected by, and any educational support they have needed. This will help:

1) To provide information for patients and their families, so they can plan for the life-long effects of CDH.

2) To provide information for designing health and education services to meet the very specific needs of CDH patients, minimising disruption in their lives and optimising their health and wellbeing.

3) COngenital Diaphragmatic hernia: Inhaled NO vs intravenous Sildenafil (CODINOS) trial - Professor Dick Tibboel - Sofia Children's Hospital, Rotterdam

Current situation:

In newborn infants with CDH high blood pressure in the lungs (pulmonary hypertension) is a major determinant of illness severity, including survival. A number of drugs have become available in recent years to treat pulmonary hypertension. However, there have been no studies to identify the most effective treatments. As a result there is wide variation in treatments between hospitals and countries, which may lead to significantly different outcomes for individual CDH patients.

How this research will help:

This is a collaborative project between international hospitals treating CDH. The study will compare drugs to treat pulmonary hypertension and identify which is most effective. This information will then be included in international guidelines, to ensure that all new born infants with CDH receive the optimal therapy, potentially resulting in better survival rates and long-term outcomes.

4) Prenatal maternal sildenafil administration to prevent pulmonary hypertension due to congenital diaphragmatic hernia: final preclinical steps to a clinical trial - Professor Jan Deprest - Leuven, Belgium

Current situation:

Congenital diaphragmatic hernia (CDH) has a high mortality and morbidity. The condition starts already in the womb by disturbed lung development. This causes problems after birth both with respiration as well as high blood pressure (pulmonary hypertension-PHT). Ideally these problems are prevented by an intervention before birth, while the lungs are still developing. We have developed a fetal operation that lessens respiratory insufficiency, but it seems to address the problem of PHT incompletely. Therefore we research alternatives that ideally treat PHT better, and would obviate the need for surgery. Sildenafil is a drug that is given to adults and infants with PHT, because it widens the lung arteries. We and others have demonstrated in two animal models for CDH that giving sildenafil to the pregnant mother restores the structure of the lung vessels and improves airway development by the time of birth.

How this research will help:

To enable formal testing of the drug in women, some steps are essential, including (1) establishment of efficacy and safety of sildenafil with CDH (2) perform studies on donated human placentas to define the dose needed in women and attain effective levels in the fetus.

We will receive regular updates on these research projects, which we will make available to the public.

We have also donated £10,000 to DHREAMS in The United States, which is an ongoing research project looking into the possible genetic cause of CDH. You can find out more about this on our website over the coming months. We will also be encouraging families to take part in genetic research and will be providing full details on this in the New Year of this new partnership.

ERNICA & EPAG

Earlier in 2017 CDH UK was invited to become part of ERNICA; a new European Reference Network for Congenital and inherited intestinal and Abdominal wall abnormalities, which includes Congenital Diaphragmatic Hernia. The initiative is led by the European Commission and consists of experts from all over Europe, including the UK. We were very pleased to accept our new role of advisory board member, to act as consultants and to help to create care pathways and better outcomes on a European level for CDH patients. This led to CDH UK also becoming a European Patient Advocate Group (EPAG) for EURORDIS - The European patient alliance for Rare Diseases. Beverley Power our Secretary is our nominated representative.

We attended the first ERNICA meeting in Rotterdam in April 2017 and attended our first EPAG meeting in December 2017. So far we have met other like minded groups in Europe and we are enjoying sharing our knowledge with others and to learn new things from our new role. This should help to ensure that CDH patients throughout Europe will receive good quality support and better access to treatments, which should lead to better outcomes in the long term. We are looking forward to working on these projects and being part of a committed team helping to make a real difference.

Picture: ERNICA members including Beverley our Secretary.

International CDH Workshop 2017

Alder Hey Children's NHS
NHS Foundation Trust

UNIVERSITY OF LIVERPOOL

CDH Euro-Consortium

CDH UK sponsors International CDH conference

This year CDH UK was proud to sponsor the International Medical event that brings together specialists, researchers, other medical professionals and patient organisations under one roof for two days of lectures and presentations on research and study findings and results, that help to improve outcomes for CDH patients and their families. This is an extremely important event for CDH UK as it enables us to keep up to date on research and the treatment and management of CDH and to also be able to share our information and findings. It's also an excellent networking opportunity.

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2017's workshop was held at The Institute in the Park, Alder Hey Children's Hospital in Liverpool and organised by a local team headed by Professor Paul Losty and assisted by CDH UK. This event takes place every couple of years in collaboration with the International CDH study group and the CDH Euro Consortium and CDH UK was very excited to sponsor and help to host this year's conference.

The event was very well attended and we heard some very exciting and interesting presentations from some of the leading expert Clinicians from around the world, and none more groundbreaking than Professor Alan Flake's futuristic like talk on the possibility of treating babies in an artificial womb. Could this be a future treatment option for CDH babies?

CDH UK's Secretary Beverley Power presented results from a feeding survey undertaken in Autumn 2017 and these results will be published on our website in 2018.

Professor David Field from Leicester University updated us on the work undertaken so far with the British Association of Perinatal Medicine and an expert consultation panel (that includes CDH UK), for the development of a postnatal care pathway in the UK, following the published MBRRACEUK report on the results of a CDH confidential enquiry and in response to CDH UK's subsequent recommendations.

We also heard from worldwide centres about their CDH experiences of treating this challenging condition, and from researchers and PHD students. The presentations were listed under the following sectional topics :

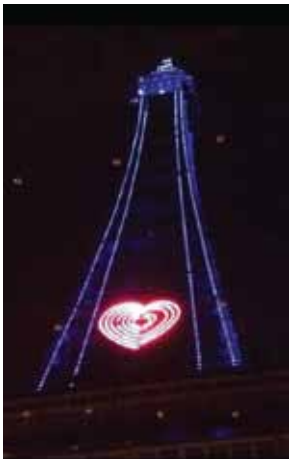
- Fetal CDH
- Perinatal management and stabilisation
- Surgery and CDH
- Science and CDH
- CDH patient outcomes
- CDH registries and networks

The CDH Study group updated us on their database and experiences to date and the Euro CDH Consortium updated us on their work and in particular their patient follow up studies and experiences.

We simply could not tell you about all of the presentations here, but you can read some of the guest research articles on our website under the research section.

Awareness Day

CDH Awareness Day is held on the 28th June each year and is a day to raise awareness of Congenital Diaphragmatic Hernia (CDH) to both the public, healthcare professionals and other organisations. It is also the date that CDH UK was founded and a celebration of the day that CDH support became available on a national level to all those affected by CDH.



This year we saw the Blackpool Tower lit up in our charity colours (pink & blue) and the CDH symbol projected in the centre of the tower. We also ran our annual Bake 4 Babies and Bike 4 Babies fundraising initiatives and we also rolled out our first 'Forget Me Not' campaign, where we encouraged the public to plant pink and blue forget me nots in recognition and memory of those whose lives have been taken by CDH. We were also featured in a supplement of The Guardian newspaper.

Our main awareness initiative was our CDH Core Challenge, which was to highlight how CDH affects a sufferer's core strength and therefore impedes on normal every day activities like standing, walking and even going to the toilet! It was also to highlight the diaphragm's role in core strength as well as the lungs to undertake strenuous exercise and how this is often taken for granted in a healthy individual. We would have liked to have seen more people take part as this could have easily gone viral, but we would like to thank those of you who did participate and sent in your videos and pictures.

We now have awareness frames that you can add to your facebook profile pictures that help to raise CDH awareness all year round, simply search for CDH on the facebook frames application and choose from 3 designs, but please make sure that you use the official CDH UK ones!

We hope that you will help us to make our 2018 CDH Awareness Day a huge success!

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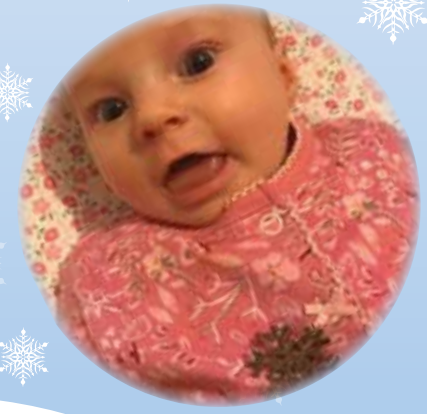
Sponsor a Snowflake Festive Appeal

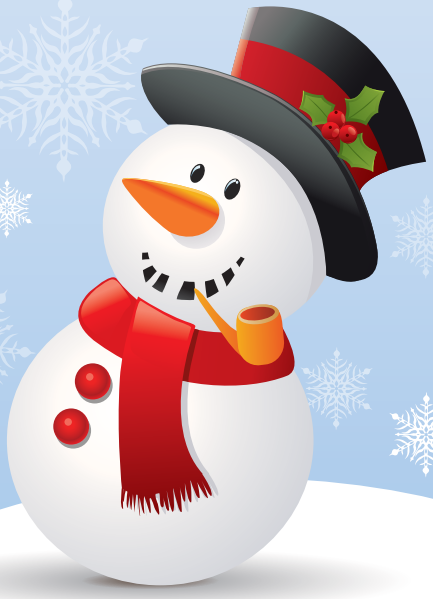
For the festive season we have again run our Snowflake Appeal to raise funds for our CDH UK Research Fund, which is now heading towards the 1 million mark with half a million of this already being donated to CDH research in 2017.

This year we ran our Sponsor A Snowflake appeal, whereby for £5 sponsors received a beautiful snowflake badge to proudly wear in recognition of their sponsorship and a donation was made to our Research Fund. The response to this appeal has been amazing so far and has helped to raise over £4,000 in a couple of weeks. Sponsorship is available until the badges run out of stock and will be available again in a new design for Christmas 2018 which makes them collectable too!

Thank you all so much for helping to create a snowstorm of sponsorship this year and to keep funds fluttering in to our Research Fund.

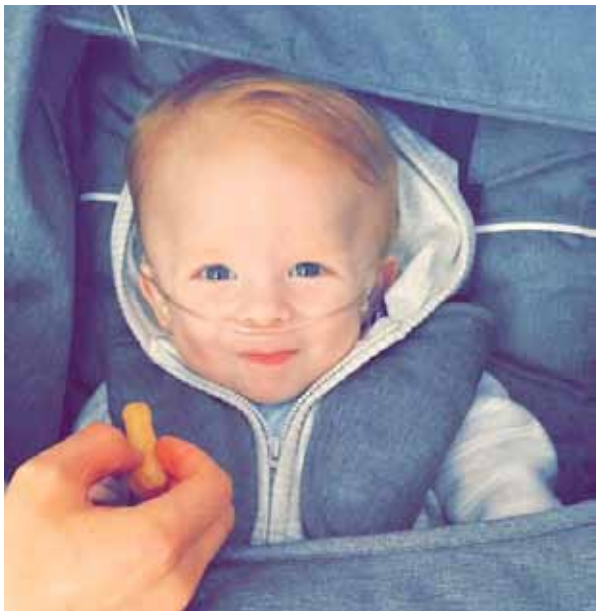
You can find the link to the badges on our facebook page and website.



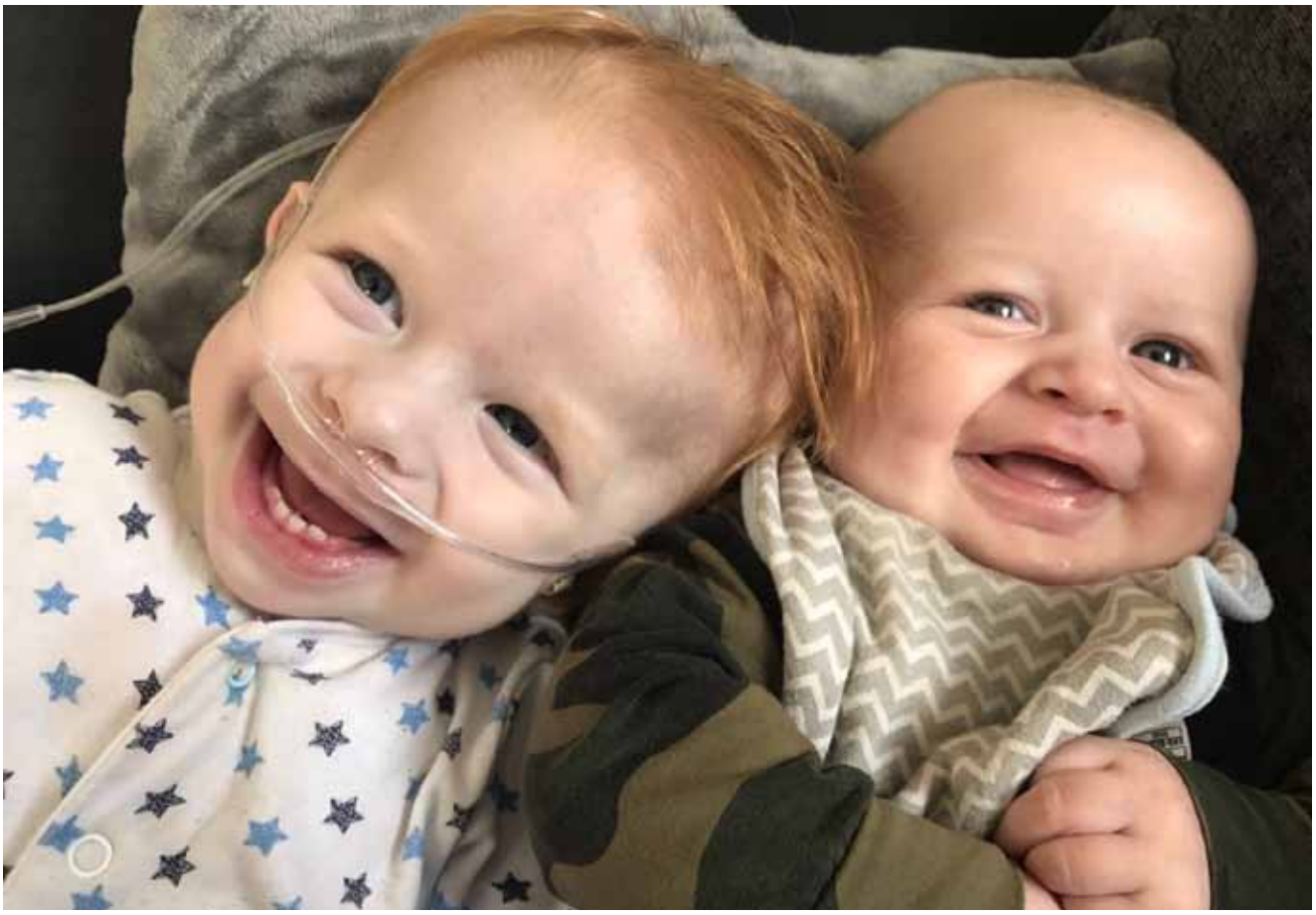


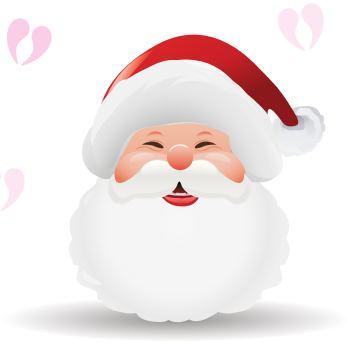
CDH Stories

Ronnie Connor Turner

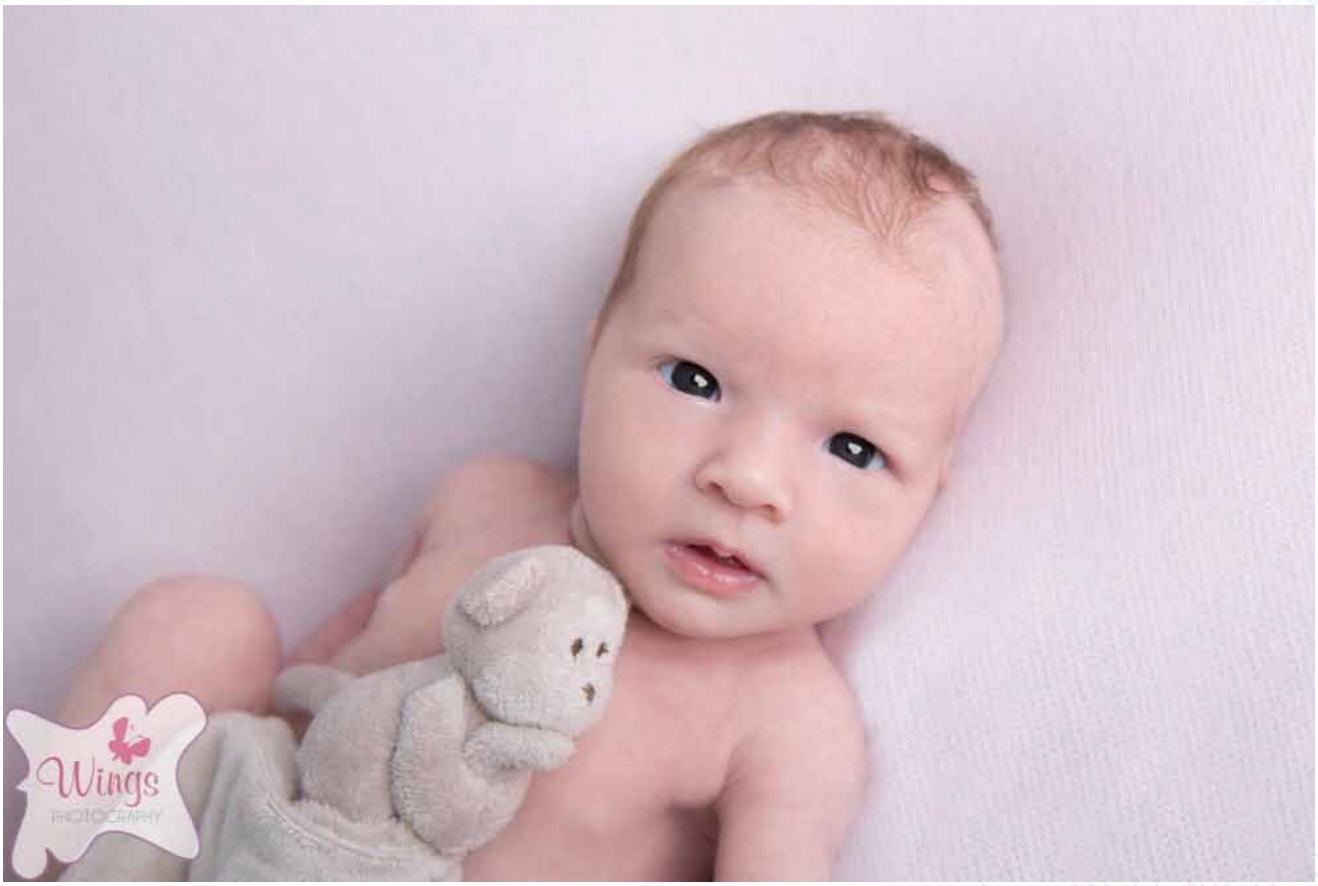


Ronnie Connor Turner was born on 27th November 2016 with an undiagnosed diaphragmatic hernia on his right side, his right lung was so squashed that it is only half of the size that it should be and due to it being undiagnosed the medical staff actually ended up putting a hole in his strong lung (the left side) when trying to help him and he very almost didn't make it past only 6 days old but thanks to the incredible nicu teams at Norfolk and Norwich hospital and also at the Glenfield hospital in Leicester he is now coming up to his 1st birthday and still fighting.





Charley Jaye Turnbull

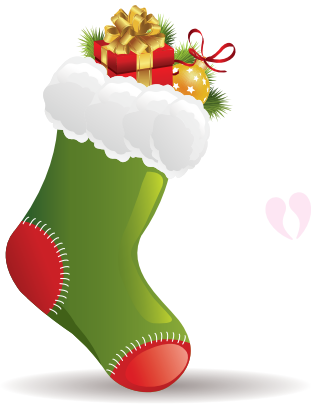


My first baby, a little girl was born on the 11th August and was post diagnosed with a CDH.
As you can imagine this was a complete shock which ripped our hearts out. We spent the first 16 days of her life in Queen's Medical Centre, who were amazing and gave our daughter the best possible care but also us as her parents.

She had her surgery at 5 days old, they were able to stitch her hole and she made a fantastic recovery, the surgeons couldn't believe how well she recovered.

Here she is, our gorgeous little princess, Charley Jaye Turnbull…

…then - just one day old and wired up and swollen.



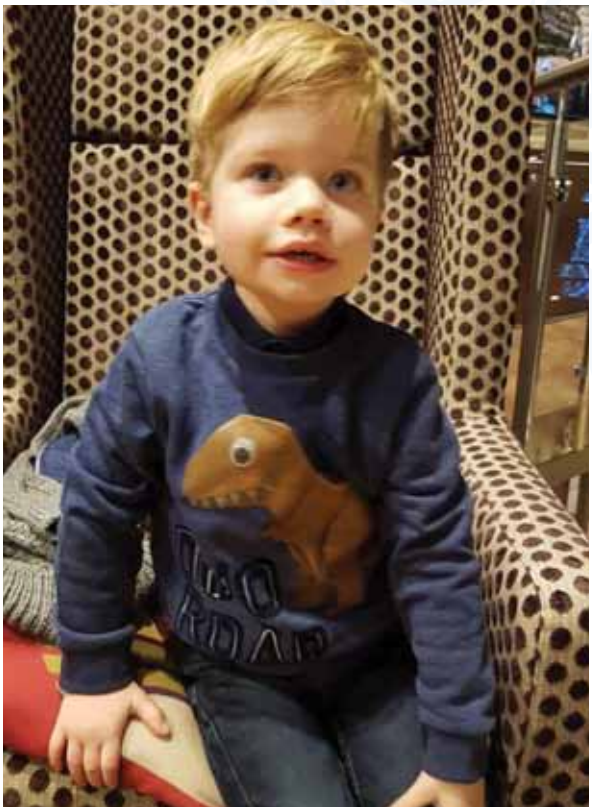
Elvey

I had never heard of Congenital Diaphragmatic Hernia (CDH) before, but the moment I heard those words and it was explained to me, my whole world was turned upside down.

I had not had a great pregnancy, I had a lot of sickness and dizziness all the way through, and when I was around 29 weeks I was diagnosed with having Polyhydramnios (excess fluid) as I was measuring much bigger than I should have been. I was then monitored much more closely, and had more scans and check ups. I had read that Poly-hydramnios can be an indicator of a birth defect, however I was assured by the hospital and my midwife that everything was fine.

I went into labour at almost 38 weeks, and after a very long and tiring 48 hours, my little boy Elvey was born at the QEH in the theatre by forceps. As I was exhausted from the labour, and still being attended to, my husband held our gorgeous little boy for about 5 - 10 minutes, he seemed absolutely perfect. The midwife then took him to one side to be weighed, but almost instantly she shouted that he'd stopped breathing and had gone floppy. At this point the alarm bell was sounded, and what felt like about 15 people rushed into the theatre, and my little boy was rushed off to NICU. My husband and I were in total shock as to what was happening, and at that point were not told anything.

I was then in recovery for quite some time as I'd had quite a difficult labour, had haemorrhaged, and due to the shock I felt freezing cold and was shaking uncontrollably. My husband went to NICU to try and find out what was happening, but again they couldn't tell him anything as they were still doing tests. Once I had been taken onto the ward of the delivery suite, my midwife came and told me that Elvey couldn't breath at all on his own and was on a ventilator. It was some time later that she returned to tell me the news that just changed our world. We were told that Elvey had been born with Congenital Diaphragmatic Hernia, which is where there is hole in the diaphragm and the contents of his stomach had pushed through the hole into his chest, stopping one of his lungs developing fully and had pushed his heart to the wrong side. We were then told that he needed life saving surgery with only a 50% chance of survival. Unfortunately we were told that this condition could not be dealt with in QEH Kings Lynn, and he had to be transferred by the ANTS team (special Neonatal ambulance), across to the Norfolk & Norwich University hospital for the surgery. My little boy was brought down to the ward in a special incubator ready to be taken miles away to another hospital. I briefly saw him through the glass, then he had to be whisked away with the team looking after him.

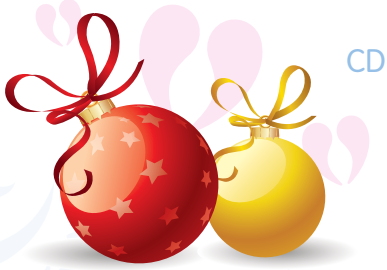


It was then early hours of the morning, so weren't told anymore as to how he was until a few hours later. Norwich hospital had managed to get him stable, so instead of operating straight away as first thought, they said they wanted to give him a couple of days to try and get him stronger ready for the major surgery.

After being discharged 24 hours after he was born, my husband and I rushed straight across to NNUH in Norwich to see our baby in NICU. We were told not to be alarmed that he wasn't moving as they'd had to give him a drug to paralyse him, as any movement could put too much stress on his underdeveloped lung which could be dangerous. We felt like we were in some sort of bubble, and thought this is not how the first hours of having your newborn is meant to be. It's meant to be happy and joyful, with lots of cuddles with your new little bundle of joy, and excited phone calls to friends and family, not with your newborn away from you in an incubator fighting for his life, awaiting surgery, and not even being able to hold him, cuddle him and feed him. It was our worst nightmare.

We spent the next couple of days trying to get our heads around what was happening, and spent every moment possible beside Elvey's incubator. I lived over at Norwich hospital the whole time so that I could be beside him as much as possible.

On day 3 the paediatric surgeon decided that Elvey was strong enough to be able to have the surgery. We watched them take him away and we prayed that everything would go well but were fully aware of the risks of the surgery. It felt



Elvey (continued)

like the longest few hours waiting to see our precious little boy back in NICU following his surgery. He looked so tiny and his dressing where he'd had the cut seemed massive, and it just seemed so unfair that this tiny little boy had to go through something so major at only 3 days old.

The surgeon told us that the operation had gone well, but the next challenge was whether Elvey could digest anything. We weren't out of the woods yet. He said that sometimes babies struggle to digest because the gut had been handled, and it's not meant to be handled. The next few days were still worrying while they monitored him around the clock. But we were so pleased to be told that he was improving day by day.

At NNUH NICU they have 4 rooms for the babies, intensive care, high dependency, low dependency and special care. After about a week I went into intensive care and went into panic as he wasn't there. I felt sick, I wondered what had happened in the short time I'd been out of the room. Then one of the nurses smiled at me and told me he had been 'promoted' to the next room to high dependency as he was doing so well. I couldn't believe it. Our little boy was certainly a fighter.

One morning when I went in to see Elvey, the nurse that was looking after him that day said that one of the doctors needed to speak to me in a private room. I felt worried, as my husband wasn't there with me, and I wondered what they were going to tell me.

I was then hit with more news about Elvey that was hard to take in. He was diagnosed with a chromosome syndrome called 'Klinefelters syndrome', which meant that he has an extra 'X' chromosome, which could affect his behaviour and learning development as he gets older. He could also have problems going through puberty. This was another shock, and even more information to try and absorb. Apparantly it can be common for CDH babies to also have a syndrome alongside it. But we thought, we have dealt with one thing, we can certainly deal with another.

As time went on he got promoted again to low dependency and then to special care.

At almost 1 month old the surgeon and nurses said that they would soon feel happy to let him come home, which we couldn't believe. The first time that they said I could take him into my room to spend the night with me was the most amazing yet the most scary time ever. I was terrified as he was finally off of all the monitors and he was almost fully under my care, but obviously still observed by the nurses.

I couldn't believe all that he had gone through and that at 1 month old we were finally able to take Elvey home. I know we were actually so lucky, as we had read about lots of other babies that sadly do not have the same outcome as Elvey, and also a lot of babies stay in hospital much longer.

I'm happy to say that since then, Elvey has gone from strength to strength. He's had a few issues along the way with chest infections, but overall he has amazed us by growing into an amazingly strong little boy, who is now three and a half. At 2 years old he had a chest X Ray and we were told that his underdeveloped lung has now caught up with the other one, and that his heart has gradually found its way back to where it should be.

Eve Phillipson

We went for the 1st scan and were told that our baby had a high nuchel measurement and a high chance of a genetic problem and told to come back 2 weeks later for a further scan.

It was the same lady who did the original scan and it took what felt like forever, upon doing this they told us and that baby had a congenital diaphragmatic hernia.

Our care was transferred to Jessops hospital Sheffield, had scan at Jessops and he told us that it was a lcdh and explained more to us.

From then on it was regular scans and months of uncertainty worry and hope.

Eve was born on 28.12.15 at Jessops and after a fast Labour was greeted by medical team on hand to help Eve and after being intrebaited she was taken to scbu, 4 hours later we were able to finally meet her and was greeted bye a mass of firery ginger hair and after speaking with many doctors and showing us countless xrays the realisation hit us like a ton of bricks, Eve was being kept alive by medicine and machines. The FIGHT had begun, Eve was on the conventional ventilator with maximum support she had a bad 24hrs and it was getting worse they moved her onto the oscillator ventilator and it sounded like a drum and the lines increased pumping her tiny body full of medicine. New year's eve Eve was on cvvh oscillator Nitric and 14 infusions going into this tiny body and still she wasn't getting any better, we were told that there was nothing more they could do but there was a treatment called ecmo but she didn't meet the criteria. We arranged for her brother and sister to come in and see there beautiful little sister, they sat and read gruffalo to her and sat in disbelief that there little sister was laying there fighting for every breath I remember telling them that she will be fine and that all the equipment was to help her. New year's day came in and the consultant told us that she had been in talks with Glenfield hospital at Leicester and that a team was coming over to see Eve. When they had done checks they needed, we had meeting, the doctor sat us down and told us that they could not reiterate how poorly she was and there was no guarantee that they would be able to get her there let alone get her better, but there was no other option. She was not stable enough to move her to the Sheffield Children's hospital 5 minutes down road but they we were signing forms for her to be taken 70 miles away, our beautiful daughter to Leicester there were no options left.

It took them hours to get there as her oxygen dropped dangerously low but they did and thanks to there amazing work the team managed to get her on the Ecmo machine.The gloves were off, this is were the battle stepped up a notch, it was again hours before we were able to see her, early hours of the morning and was greeted by a room full of machines, tubing, monitors and inside of all this beeping and machines our little beautiful daughter and her golden ginger hair filling the room with warmth and hope.

Eve (continued)

She was on the Ecmo machine for a gruelling 13 days, on the 7th day the director of ecmo said he was going to do the lcdh repair whilst she was on Ecmo circuit so the risks had increased but this was the best time, so I signed the form gave her a kiss and we left them to do what they do best they do the surgery on the unit as they couldn't move Eve if they wanted to with all the equipment. Many hours later the surgeon and team came out to speak to us and explained that her left diaphragm there was NOTHING there and they had to use a big piece of Gortex. He then also told us that she had a mekhel diverticulum and they had removed it. We thought the battle was nearly won and after 14 days they managed to get her of the Ecmo machine and eventually she was transferred by Embrace to Sheffield childrens hospital (we were forever in there debt they managed to save our beautiful little girl their reply was "we've done the easy work the staff at SCH have the hard work to do I was in disbelief I thought the fight was all but over).

When we were able to see Eve on the intensive care unit we was met with tubing screens infusions and the realisation hit us hard again.

She remained on ICU for several weeks each day and night fetching its own problems from not stabilising her blood pressure to not being able to get access for medicines and blood transfusions.

Eve was moved onto the Neonatal surgical unit and made great progress she remained tube fed and was suffering from reflux disease and struggled to put weight on as she had part of her bowel removed and the surgeons and consultants explained because Eve has a small left lung every day would be like her running a marathon. She was struggling but that didn't stop her she still faught hard everyday and night and eventually we was able to hold her - tiny frail but ouzed love character and her golden ginger hair and smile turned anyone's bad day around.

We were finally discharged and not for the first time thought that we were winning this fight until 2 weeks at home she got rushed into Doncaster hospital with Bronchiolitis she spent 5 week's in hospital on antibiotics and oxygen and was dishcharged now on oxygen 24hr tube fed medicine for her heart reflux and so on.

We were home for 2 1/2 weeks and yet again back into hospital as she couldn't maintain sats above 80% on double her oxygen requirements.

Eve looked as if she was picking up until the following morning they did a blood gas and her carbon dioxide levels were dangerously high. They tried her on CPAP but it wasn't working so that made the decission to ventilate Eve, they tried the standard size tubing but Eve had been ventilated for weeks already and had a wider airway than normal. It was shift handover and myself and mum were in the room and heard the words NO OUTPUT START COMPRESSIONS it was organised chaos and with every minute passing by they were marking it on a white board a doctor came in with a small case and they administered adrenaline straight into the shin bone that they had drilled, they did this four times and all working simultaneously and then we heard the words got an output. They worked hard to stabilize Eve and there was even more people helping Eve and then Embrace arrived and took over in this madness of stabilizing Eve after several hours we were finally able to take a breath when they started talking about her golden locks.

She was transferred back to Sheffield childrens hospital and was on intensive care unit for several weeks while they treated her for a left lung collapse pulmery hypertension and the list of medicines increased.

We spent several weeks at home we even managed to get on a few daytrips and things were going good so we went away for a few nights to Blackpool we all enjoyed every moment of it a family spending quality time together.

Our weeks were taken up with many appointments either surgical, respiratory, cardiac, gastrology, dieticians, speech and language OR physio but life was good we were adjusting and most of all enjoying life.

Eve started to take poorly and after a appointment with her pediatrician was admitted she had a xray and there it was her diaphragm had reruptured again, so off to Sheffield she was transferred and had some blood results back and she had cryptosporidiosis she started to deteriate and the canulas didn't last 24hr before they stopped working that did a blood sugar and it was 1.4, so they tried to canulate but no luck her veins were no good as they all had been used previously and her main ones in the right side of neck had been closed off from ECMO. They then took her to theatre and had a broviac line inserted they got her sugar levels back above 4 after 3 tubes of glucogel.

Eve surgical team told us what they they intended to do repair the diaphragm and do a fundoplacation to stop the sickness of reflux and a peg for feeding.

She was in surgery from 1pm we eventually saw her at 9pm, they had to replace the previous Gortex patch from Glenfield. It was a long long day but like always she faught and came out the otherside running.

She was ready for discharge after 3 weeks and they requested a xray before we went home, but to our horror her left side lung was a complete white out and collapsed they did a broncoscopy and 3 stage wash out, nothing worked she was on nippy junior and fought and fought infection and problems she couldn't tolerate any time off and the decision wasn't lightly made to give her a tracheotomy she celebrated her 1st birthday on the high dependency unit and all the staff helped to make it a great day then 2 days later she was off to have the operation she had the tracheotomy and within a few days she was getting back to get normal self with one MASSIVE DIFFERENCE you couldn't hear her voice and that had a massive impact on us all.

Eve (continued)

It was as if she had opened her eyes for the first time you could see the expression on her face without all the feeding tubes, oxygen canulas it was free for the first free Amazing.

Eve was making excellent progress and we started the training to be able to care for her needs and then out of no where BANG - she took poorly again, that put her on antibiotics and they did every test imaginable.The results came back she had sepsis in her broviac line this has came as a massive shock to everyone they removed the broviac line and treated the infection and after a couple of weeks she was on the mend. Whilst doing ultrasounds and ct scans they had noticed a large collection of fluid running alongside her diaphragm and she also had got a wandering spleen.

She developed a large lump and they drained it this then started to leak the same colour contents as her nappy after more scans and samples sent to microbiologist it came back as fecal (bowel content) her bowel is rubbing against her diaphragm (gortex patch) and this as created a stoma so now she had a bag that allows the fluid to drain into.

Eve went back to theatre for the stoma to be cut back and also had a mi - key button for feeding.

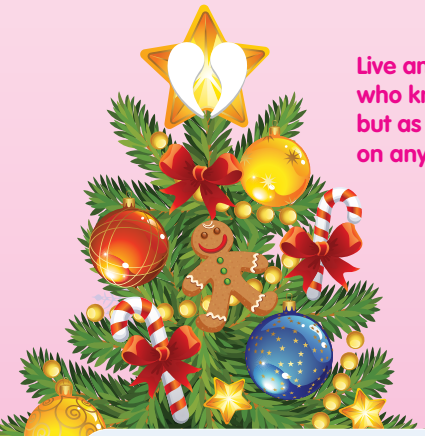
Eve has come on leaps and bounds and is now medicaly fit for discharge and is coming on amazing she is a true cdh fighter (ginga Ninga).

We have to move out of our house as it's not suitable for her to come home to and that had fetched a whole new bunch of problems. She also requires awake carers and are in the process of sorting that out.

Our life has changed so much since Eve was born our other 2 children have been amazing throughout this journey and they are also keen to help out.

Our son Kane said at Christmas that he doesn't want any toys from Santa just wants his little sister to get better and come home.

And finally after weeks of searching and trying to raise awarness of what families have to go through hospital to home and the massive impacts it has on all family members we have finally found a suitable home on to the next chapter of our life whatever it may bring.



Live and love, live today as a family as who knows what will happen tomorrow but as a family you can take on anything.

Martin Pither

My name is Sue Pither, I've recently raised £2214.70 for CDH UK through walking the West Highland Way and climbing Ben Nevis. The reason I did these challenges is because my late brother Martin Pither was born with a Congenital Diaphragmatic Hernia back on the 11th of October 1979. Martin was given his last rites at birth because after 4 operations, his biological mother nearly lost him. Thankfully Martin survived but his biological parents decided to put him up for adoption because they had marital difficulties and really didn't think they could cope with Martin's condition. My adoptive parents Bill and Wendy wanted to adopt another child and found out about Martin and adopted him. I was roughly 6 and a half years old and was delighted to have a baby brother (Martin was 6 months when he came to our family). Although there was roughly 6 years in age difference, Martin and I were very close especially as children, he made my childhood so happy. Sadly most of Martin's life he was in and out of the John Radcliffe hospital where he was born but he never complained, he was always smiling, laughing, joking and getting me his big sister often into trouble. Asthma, the use of one lung and growth problems came with Martin's condition and as a young boy he quite often had pneumonia, but always fought it like all the operations he had through out his life like a true warrior. Tragically on the 29th of September 2016 , Martin fought his last fight, his hernia had somehow tangled with his bowel and he died of sepsis. Our family were absolutely devastated, it was completely out of the blue. We had no idea that CDH UK existed either, I only discovered this amazing charity after my brother's funeral whilst 'googling' my brother's condition. What I read about CDH UK is fantastic, I just feel sad that Martin never knew about it and sadly it didn't exist whilst Martin was growing up (mum and dad could of done with the support).

None of us could have saved Martin but I couldn't sit back and do nothing, so I did my sponsored hike and climb to raise money for CDH UK. I've recently posted the cheque to the charity for £2214.70 to your Treasurer Kerrie Laird and I feel good knowing that this money will help those out there born with a CDH like Martin and will educate others too (especially the medical profession). I'd be honoured if you could feature my brother's story and my sponsored event in your Christmas newsletter (my brother loved Christmas although we lost our mum 12 days before Christmas back in 1998), he still remained cheery.

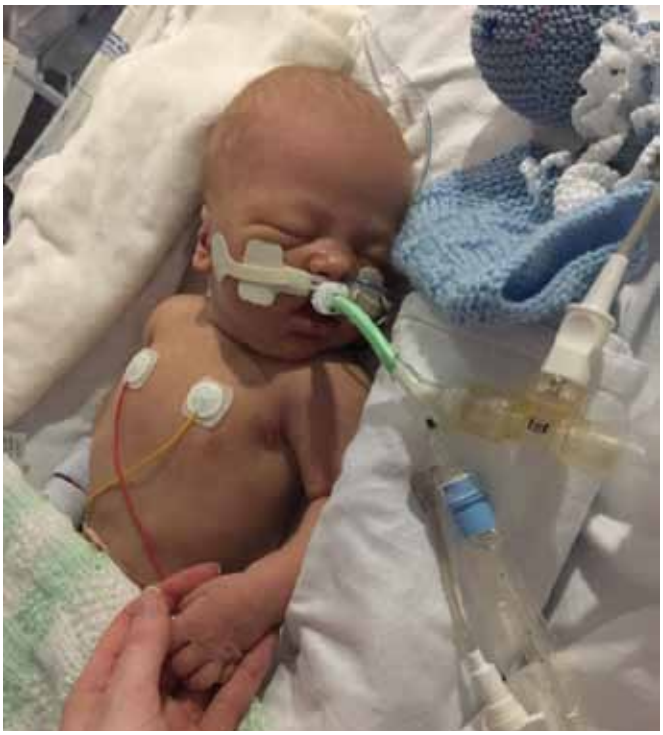
Harrison James Hughes

After what felt like a life-time of waiting I was finally 16 weeks pregnant. We eagerly awaited a private scan we had booked to find out the gender of of our first baby. We arrived excited and sat watching the people before us leave with a pink or blue bag wondering which we would leave with, blissfully unaware that life for us would change forever in a way that we would never imagine. The scan seemed to be going well at first, she told us we were having a little boy but would like us to go for a walk and come back to see baby in a better position to double check. Never did I imagine that when we returned she would be telling us there was something wrong with our baby and we would be leaving out the back entrance with no bag.

The next day I had a scan at the hospital, which confirmed our baby had a left sided diaphragmatic hernia with stomach and bowel herniated in the chest. After more tests and scans they found the condition to be isolated and so we were given a 50:50 chance of survival for our little boy. A termination was offered but we chose to give him a chance at life despite understanding what we were about to put ourselves through. Numerous scans throughout the pregnancy showed no new changes, it was just a waiting game to see what would happen when he was born. After a while I was able to enjoy the pregnancy again. I knew I had to enjoy every second I had with my son as the reality was that I may not have much time when he's born.

On the 12th of August 2017 at 11:51 Harrison James Hughes made his entrance into the world and was taken away from us immediately to be ventilated. Of corse nobody can be truly ready to go through the emotions of giving birth to then not even get to touch your baby before he is wisked away, but we were prepared the best we could be. We managed a quick glimpse as they rushed him by in the incubator to take him to intensive care. 5 hours later we were able to meet our son for the first time, we have never felt love like it, he was just perfect. Aside from all the tubes and wires he looked so healthy, it was hard to believe inside he was so poorly. For the first few hours Harrison was stable but quickly started to deteriorate and by the next evening became incredibly poorly. Despite the liver been down on all of our scans, Harrison's X-rays showed the left lobe of his liver had herniated too and along with some bowel was stuck in the hole cutting off the blood supply. Just over 24 hours after he was born in a last attempt to save him he went for emergency surgery to release the trapped bowel and liver. We were told it was unlikely he would survive so we prepared for the worst and kissed our little boy goodbye. Miraculously he survived and returned from surgery a few hours later. He remained very unwell but after the surgery he made some small improvements. Hour by hour things changed, there are no words to describe the ups and downs that NICU brings. ECMO was now his only chance and the team were called from Leicester to come and collect him. Harrison had other ideas and a couple of minutes before their arrival his oxygen levels and blood pressure dropped. The room suddenly became full of people trying to save him and just as the ECMO team arrived in the room he put out the best monitor readings and blood gases he had had since birth. At that point it was decided not to risk transport and the ECMO procedure given Harrison seemed to have had turned a corner. Unfortunately after a few hours his levels plummeted again and left him in such a fragile condition that to even move him for the ECMO procedure would have been too much for his little body to handle. Despite the continuous care of the amazing neonatal team that looked after Harrison, at 5 days old we had to make the incredibly hard decision to let him go. He passed away peacefully in his daddy's arms with us all holding hands. We got to bath and dress him and make precious memories that will stay with us forever.

Despite our loss we still feel incredibley lucky to have met our little boy, to have held him in our arms and to have had the chance to show him how much we love him. Harrison has taught us what is important in life, and we couldn't be prouder of our little fighter. Nobody wants to end up on this side of the 50:50 statistics but we would do it all over again if it meant 5 more days with out precious little boy.



John Robert Foxall

John Robert Foxall is currently enjoying life in Year 1 at his local primary school. He is happy, active and has a great imagination. He loves dressing up, particularly as a policeman when he enjoys arresting everyone in sight. He lives life to the full and this is his story.

It began with the 20 week scan which was all full of excitement until the dreaded silence from the lady scanning. 'I think he may have something called CDH' she said 'it probably isn't but I am going to refer you to Birmingham Women's Hospital for further scans. I wouldn't worry at this stage and don't go looking it up on the internet.' Although we were worried, we didn't Google CDH. In fact, we only did this after he was recovering from his first operation. This was a decision that in hindsight for us, I am glad we made.

After many regular ultrasound scans, an MRI scan, amnio-centesis and great care and explanations from the various staff, nurses, Doctors, consultants and surgeons at both Birmingham Womens Hospital and Birmingham Childrens Hospital, John was born, a week early by caesarean section on Thursday 5th July 2012. His heart rate was dropping and this was his way of telling us he wanted to get out, get on with the operations and get on with life. There were 14 staff in the delivery room, a brief cry from John and then he was sedated, intubated and whisked away, not to be seen by me for a couple of hours and his Mom even longer due to her own operation. The staff though were great as they took some photos of him once he had been stabilised and brought them to us early on. This was the first time we 'saw' John.

We were lucky enough to be given accommodation in the hospital and so were able to visit John all the time. But John was quite poorly. He was on HFOV and Nitric Oxide for a week and it was very touch and go for a while whether he would be well enough to be operated on. He didn't seem to want to wake up when his sedation was weened down and he had quite a few wobbles over the next few days, often prior to relatives coming to visit. We seemed to spend most of our time gazing at his monitors, willing the numbers to rise. I always remember asking one Doctor how he was and received the reply 'Flagging'. That was the first time I think that the severity of John's situation hit home and I still dislike that word to this day.

However, on Saturday 14th July John was transferred to Birmingham Children's Hospital's PICU around Midnight. The next day John underwent a 7 Hour operation to repair his left side diaphragmatic hernia alongside having a canular fitted to his neck, his malrotation corrected and his meckel removed. These were the longest 7 hours ever. Attempts had made to make his repair via laparoscopy but his herniation was too big and so it was through John's chest that his procedures took place. His abdomen had to be left open and he was returned to the Intensive Care ward. Again we were lucky enough to have been offered accommodation nearby, this time at Ronald Mac-Donald house and so were able to spend lots of time with John.

Over the next few days there were further wobbles, blood transfusions and an occasion where the emergency alarm was pressed for John, with all available staff coming to his aid as he needed resuscitating. It was a worrying time but thankfully John pulled through.

The day after John's operation to have his abdomen stitched up on Thursday 19th July was the best day so far. First cuddles! His Mom was able to cuddle him for the first time, 15 days after he was born.

On Saturday 21st July John was transferred back to BWH around 10pm and again we were gratefully able to take up residence in parent accommodation. Chylothorax then built up in John and a chest drain was fitted before being removed due the cause being discovered. John had to be taken off EBM and put on Monogen milk, this was heart-breaking as it was the one thing we seemed to be able to do to help him (his Mom producing the milk and both able to tube feed him), as often we felt helpless in his recovery.

Over the next couple of weeks John steadily improved although there were a few more wobbles along the way and he again gave cause for the emergency button to be pressed. A heart stopping moment again, for both him and us.

John was not keen to be taken off his ventilator but after 2 failed previous attempts he decided he was ready and pulled out the tube himself and he was put on CiPap, which was a great step on the road to recovery.

John (continued)

We are from Stafford and so it was time to be moved nearer home and on Wednesday 8th August John was transferred to PICU at North Staffordshire University Hospital. Always one to keep us on our toes, John decided to have a wobble in the ambulance causing it to have to pull over mid journey. Thankfully he pulled through. Over time his CiPap was reduced and he was put on Optiflow and eventually O2. He was now well enough to be transferred to the Children's Ward, although still tube fed. Again we were very lucky and were provided with accommodation at this hospital.

On Monday 20th August it was time for tears of joy as John was moved one step closer to home. This time to Stafford General Hospital as it was then known. After 8 days he was discharged and came home. He was on oxygen due to having hardly any left lung, (which also means he has Pectus Excavatum) and was also still having to be tube fed, but he was home.

There were many visitors to help us look after John, the District Nurse, SALT, Physio, Health visitor etc. and his 02 level was monitored frequently.

On Wednesday 10th October X-Rays were taken at Stafford Hospital to see if John was ready to take EBM and although we were very pleased that the answer was yes, the X-rays sadly showed that John had reherniated and a second diaphragm repair was needed.

On Wednesday 17th October John was admitted to ward 9 at BCH and after several postponements over the next couple of days he had his operation on Saturday 20th October. He was then transferred to the Neonatal Surgical Ward but began to experience breathing difficulties (due to excess fluid on his lung) and had to be rushed to PICU and intubated. Again we were lucky enough to be accommodated at Ronald MacDonald House which allowed us to spend maximum time with John at this worrying time. Thankfully, with the help of one particular nurse and a team of Doctors who asked what had worked last time on John to ween him off ventilation, he was extubated and through a variety of gizmos and contraptions was weaned back down to his regular O2 over a number of days.

A week later John was moved back to ward 9 and on Monday 29th October was discharged from BCH.

John was home again and in January had his NG tube removed and thankfully was taking his milk well. Unfortunately on Wednesday 9th January 2013 it was confirmed via an Ultrasound head scan at Stafford Hospital (requested by BCH due to John's large head) that he had now developed Hydrocephalous. He was kept overnight at the request of BCH before being taken there by ambulance the next day.

After an MRI scan on Friday 11th January John was allowed home leave for the weekend. Yet again we were fortunate to be able to reside in Ronald Macdonald house and always be close to John, with one of us by his bedside and one not too far away at night.

On Wednesday 16th January 2013 John had a successful shunt operation and was discharged the following Monday.

It had been a tough 6 months for all of us and the hope now was that John was able to truly start to recover from his hospitalisations. It seemed like over the next few months John started to become even more of our son and less of a hospital patient, particularly as he was gradually weaned off various medications, his oxygen and as his number and frequency of medical visitors decreased. By John's first birthday he was on 02 only at night and by September he was off it completely.

However, an X-ray in October showed that he was developing Scoliosis and he was referred to Birmingham Royal Orthopaedic Hospital. He had also developed a hydrocele possibly caused by fluid built up from his shunt.

On Monday 27th January 2014 John had an X-ray at The Royal Orthopaedic Hospital Birmingham which confirmed he had a 17% curvature of his spine and mild Scoliosis which was monitored. He eventually required a brace, which was fitted in March 2015 and is to be worn 24 hours a day.

John's Hydrocele was also gradually getting worse and by July 2015 he was on the list for another operation which took place on Saturday 22nd August with John being discharged the day after. However, things were not right and John's Hydrocele began to return and enlarge very quickly. After a visit to the Doctors I took John back to BCH A and E on Monday 24th August and John was re-operated on the day after. It turned out that on top of everything else John was a mild haemophiliac which explained his continued and excessive bleeding. On Thursday 27th August John was discharged, again.

John (continued)

In 2016 John's Hydrocele unfortunately reappeared and later on in the year was put on the waiting list for an operation. Whilst awaiting this operation John became unwell, sick and very tired, all signs of a shunt malfunction and so on 1st June he returned once again to BCH to have operation number 7 a shunt revision. All went well, with the haemophilia team now playing a big part in John's operations and recovery. John was soon back to his normal self and allowed home after a number of days.

Unfortunately, almost a year later John was taken ill again and had to return to BCH. His shunt had malfunctioned again and after a couple of days of observations and scans it was again replaced. With his haemophilia he was kept in for a few days but thankfully all was well and he was soon discharged.

After a long wait John was finally given a date for his third Hydrocele operation and on Friday 21st July 2017 he was admitted to BCH, operated on and on Tuesday 24th July discharged. This was John's 9th operation and hopefully his last for a while.

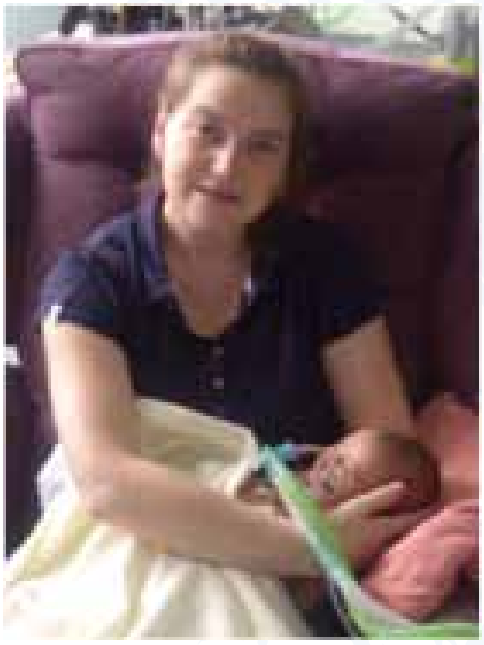
John takes everything in his stride and has certainly been through a lot in his first five years. He has had a tremendous amount of support from various professionals including attending a special school one day a week before he began nursery. This was to help with his delayed physical development, which along with delayed speech could possibly have been due to CDH or his Hydrocephalus.

His CDH does not seem to be giving him any problems at present and all appointments regarding this have been good. His absence of a left lung does not seem to be holding him back and he gets up every morning, far too early but always raring to go. Outwardly John is just like any other 5 year old, he loves castles and armies, wizards and magic, parks and play barns and is particularly fond of dressing up as mentioned earlier.

John's journey has not been an easy one and one which medically is always going to be on going. However John is an inspiration and we hope that reading this has been of interest, comfort or use to you. Although not all of it concerns CDH it does show that children with CDH can often have other medical issues. It also shows that as one of the Doctors said to me way back when John was only a few days old and I asked him about his chances "you have got to have hope, for without that, what have you got?". We certainly had hope and are truly thankful for all the people that have got John to where he is today.

Richard and Dawn Foxall

Proud and thankful parents of John Robert Foxall, 5.



Oliver James Jacklin

When I fell pregnant with Oliver James, I was terrified to tell my parents: but I was happy knowing that I was having a baby and I fell in love with him. When I saw him on the 12 week scan, it was amazing to see his heart beat and to find out when he was due.

At 20 weeks I found out I was having a boy. I was stuck on boys names as I only had girl's names. Whilst the scan was taking place I found out Oliver James had a Congenital Diaphragmatic Hernia. I was scared finding this out; but I always had hope he was coming home and that he was my miracle baby.

A few weeks after the scan I had chosen the name Oliver James due to it being the only name I liked; and James as that's my dad's middle name. Throughout pregnancy I was talking to him; reading Disney stories, calling his name – and he used to respond by moving or kicking; which was really reassuring.

Throughout pregnancy, I had 14 scans. This was to check Oliver James' development and to check on the Congenital Diaphragmatic Hernia – his stomach, bowels and part of his liver were in his chest; and because of such, had pushed his heart onto the opposite side of his chest. They would check his heart to see if was ok, with it being pushed over to the right side. Due to this, I was given a 50/50% chance of him surviving. When I felt Oliver James move and watched him on scans, it used to make me feel happy knowing he was my special little boy.

I became a proud and devoted mum to Oliver James Jacklin; who made his appearance on 1st August 2016 at 8:41pm; weighing 6lb 9oz at Newcastle RVI Hospital. He was baptised at 2:45am on the 2nd August 2016, as medical professionals thought he wouldn't survive the night.

At approximately 6:10am, when the Leicester Glenfield Hospital team arrived, Oliver James was put on ECMO (extracorporeal membrane oxygenation). ECMO took the blood out of his body to oxygenate it before putting it back in. Once Oliver James was all set up on ECMO, I saw him and gave him a kiss before he set off to Glenfield Hospital in Leicester. My dad went down with Oliver James so he wasn't alone, dad updated me when he arrived at the hospital informing me that Oliver James was moving about, opening his eyes and grasping his finger. This made me hopeful that my little miracle was doing well.

On 3rd August 2016 I arrived at Glenfield Hospital in Leicester. I was unable to leave Newcastle RVI Hospital any earlier, as the hospital would not discharge me due to Oliver James being born by caesarean section. When I arrived on the Paediatric Intensive Care Unit at Glenfield I was overwhelmed, I started to become emotional and cry; due to Oliver James looking so much better as he had a better colour than at Newcastle. All the medical staff made me and my family exceptionally welcome, asking how we were all doing? The Glenfield Paediatric staff explained what was happening with Oliver James; which was reassuring.

On the 4th day of August, Oliver James was able to have his surgery – this was to move his stomach, bowels and liver out of his chest and back to where they should be. After the operation, I got told that everything had gone well. The staff involved me and allowed me to do some of Oliver James' care. I was happy being given the opportunity to do this, but was nervous at the same time; due to all the tubes.

Oliver James having been born with Talipes, a condition I too had been born with; I was allowed to do his physio. As it had turned out, him developing this condition, there was no doubting that Oliver James was definitely my double. He was a little monkey when it came to doing his physio. I think he knew I was doing it, and therefore decided to resist.

The paediatric staff also allowed me to do his eye and mouth care. I also managed to wash him on 2 occasions and changing his nappy once; I will cherish these memories forever; especially when I remember kissing him. I got gis grandma involved in his care to allow her to bond with him. I always felt hopeful and thought Oliver James was going to come home due to him fighting everyday, which I'm proud of. When I asked how he was doing I was told he was doing fine.

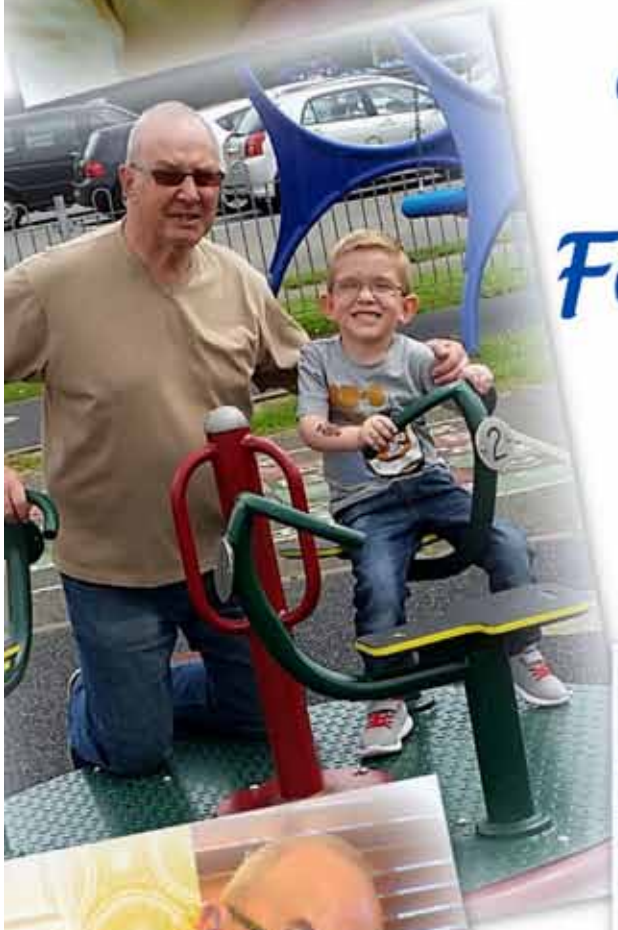
When we used to see Oliver James on the ward he used to be a little lazy, yet another trait of mine; and he decided he would only open one of his eyes a little. Until later in the week he decided a few times that he would open up both of his eyes whilst I was washing him.

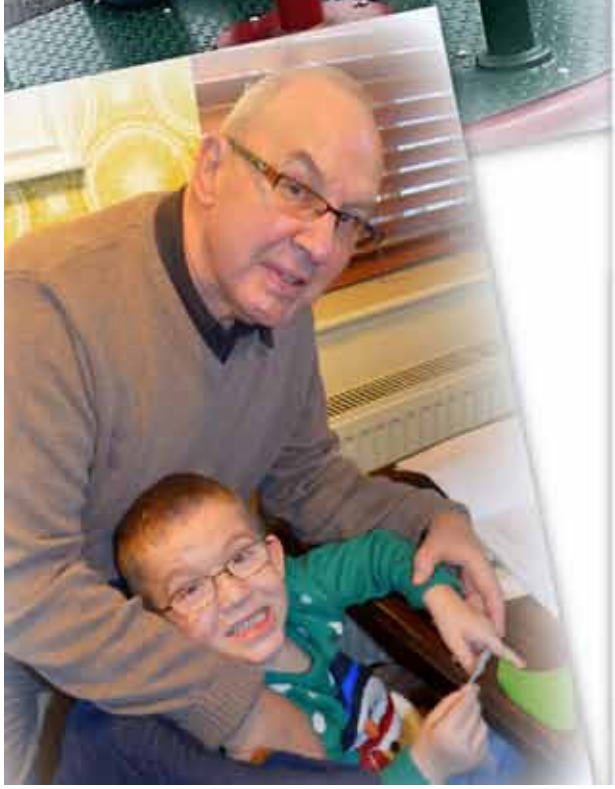
When seeing his lovely blue eyes it made me fall in love with him even more. He was so beautiful! On Monday 8th day of August 2016 Oliver James became unwell and suffered from internal bleeding to his lungs; which caused him to pass away at 7:41pm and gain his angel wings. My little angel will always be in my heart.

I would just like to end by saying I only knew my little boy for seven days and in that time it has been an emotional rollercoaster but, I wouldn't have changed it for the world. I have gained some wonderful memories whilst I have been in hospital caring for my beautiful little boy.

I told my mum that I was scared to talk to Oliver James as I didn't know what to say, but then I started to talk to him – this made me fell emotional but positive. Every day I was asking how Oliver James was doing, and all the time was hearing positive news, I can only say, I am 'SO PROUD' of my little fighter.

I cannot thank the staff at Glenfield Hospital, Leicester enough for giving me and my family more time with my beautiful little boy. The members of staff are professional, caring for their patients as well as family, and supportive. I really appreciate everything that they have done for Oliver James, myself and family.





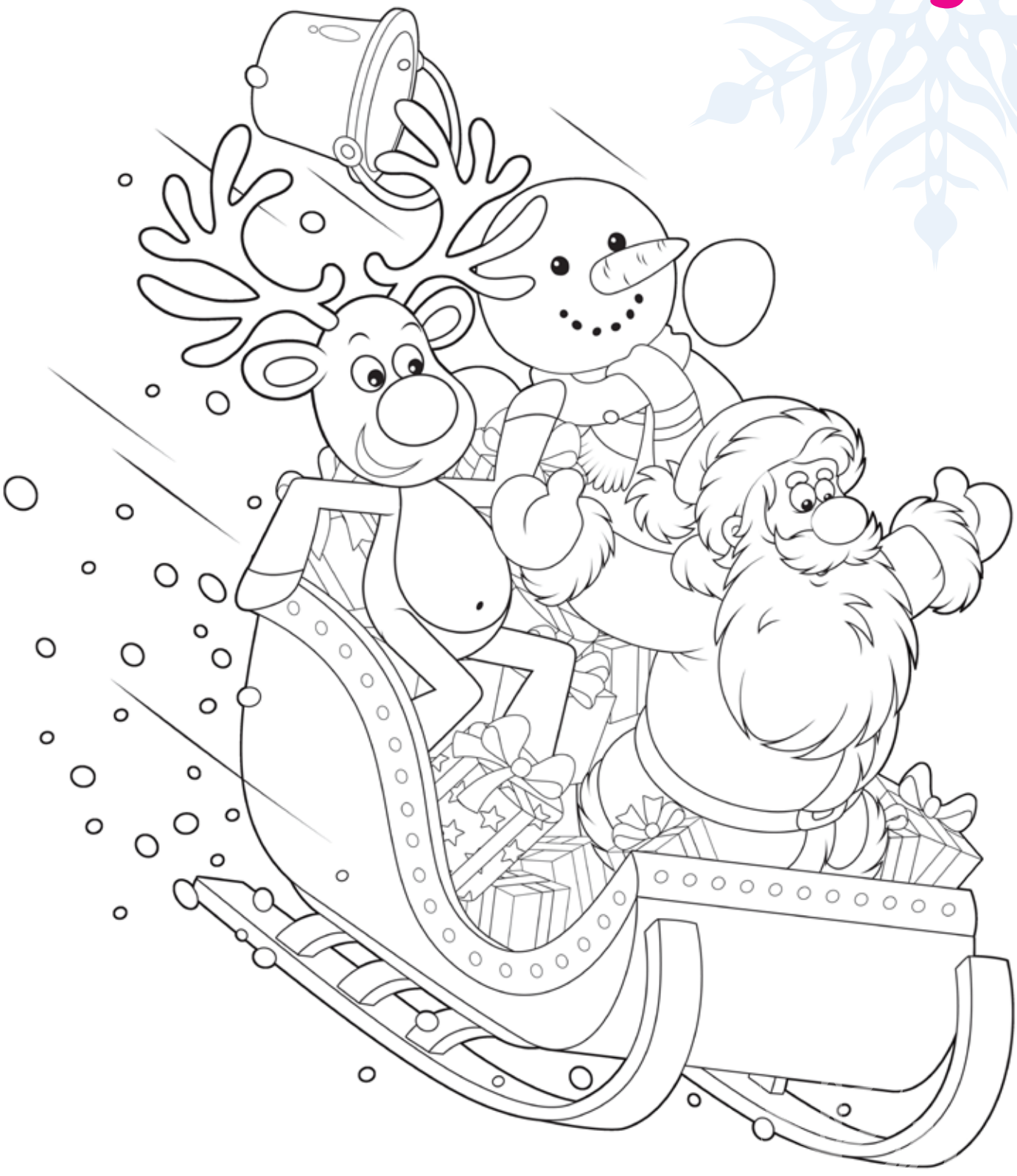
To Celebrate Callum's 7th Birthday, & the life of his Late Grandad Dave, our Family & Friends have raised

£115

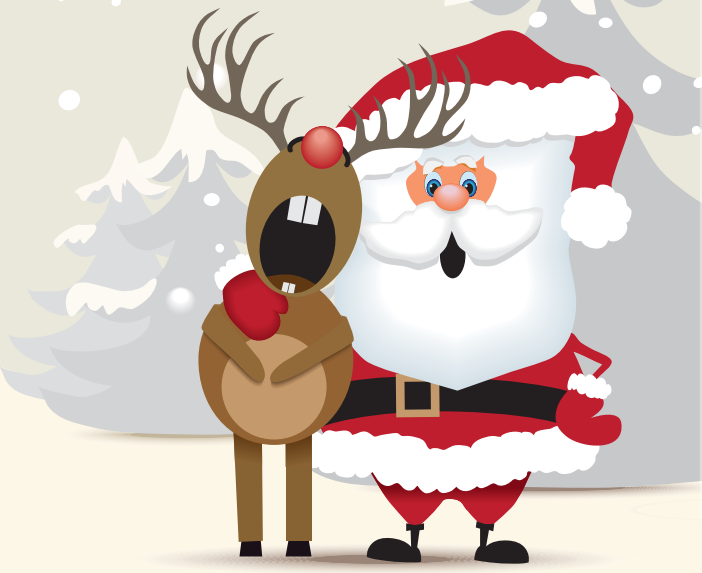
for

cdh UK

Colour in Santa in his sleigh



Christmas Word Search



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a w a y i n a m a n g e r e e
n a m w j n s a n t a b a b y

Away in a manger
Jingle bells
Let it snow
Little St Nick
Rudolph
Santa baby
Silent night
Last Christmas
Deck the hall
Silver bells
Sleigh ride
Jingle bell rock

Useful websites

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

Asthma UK
www.asthma.org.uk

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

Bounty - Support for new parents
www.bounty.com

British Heart Foundation
www.bhf.org.uk

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

CDH UK webshop
www.giveasyoulive.com

Child Bereavement UK
www.childbereavement.org.uk

Contact
www.contact.org.uk

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

Medical Research Articles
www.bmj.com

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

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

Virgin Money Giving
www.virginmoneygiving.com

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