The CDH Magazine

EDITION 3 2022

Hello and welcome
to our 2022 edition of The CDH Magazine!

I am so happy to be sat here once again writing my welcome and recalling all of the wonderful work that the CDH team has carried out to continue to support patients, families, healthcare providers and anyone else affected by CDH. It has also been humbling and inspiring reading your stories. They really do help others, whether that is a patient, parent or healthcare professional, they can offer information, hope and comfort.

It has been another year of change for everyone with new Primeministers to get used to and the very sad passing of HRH Queen Elizabeth II who did so much work for charity during her reign. You can read our full tribute on our website. We of course wish our new King all of the very best for the future.

No doubt all of this change has been particularly difficult for some of you and perhaps has brought up memories of difficult times, changes and loss in your own personal lives. Remember our motto is 'we are always here'.

Your support is so important to us and we have seen another year of fantastic fundraising efforts. It is of course difficult to ask for donations during a cost of living crisis, but it also inevitably impacts on our voluntary income. We have decided not to order any new festive merchandise this year, but to discount our existing stock and for our Snowflake Appeal this year we are giving you the opportunity to obtain our limited edition Jubilee medal for a suggested donation of £5. We are so grateful for every donation and fundraiser no matter how small.

My own thoughts have turned to how we can help patients and families and support them through this crisis. We currently have our Financial schemes that we hope will continue to help the families that need it and we are currently urging families who are facing difficulties with children or relatives requiring home ventilation, oxygen supplementation, feeding machines or any other type of therapy requiring energy usage, to contact us for support and advice.
We hope you enjoy the following pages of information and inspiration and thank you to all who contributed.

I want to finish by saying that the festive spirit brings comfort to many people for lots of reasons and the CDH UK team hopes that you find peace and goodwill, and that 2023 brings better times for us all.

Until next year!

Lots of love
Bev & Team

cdh UK The Congenital Diaphragmatic Hernia Charity

CDH Research HUB

Research has again been a huge focus for CDH UK despite the challenges we have faced and we are very proud to have continued to receive donations into our Research Fund and to be able to fund and co-author various research projects and papers that we hope will improve outcomes for patients.

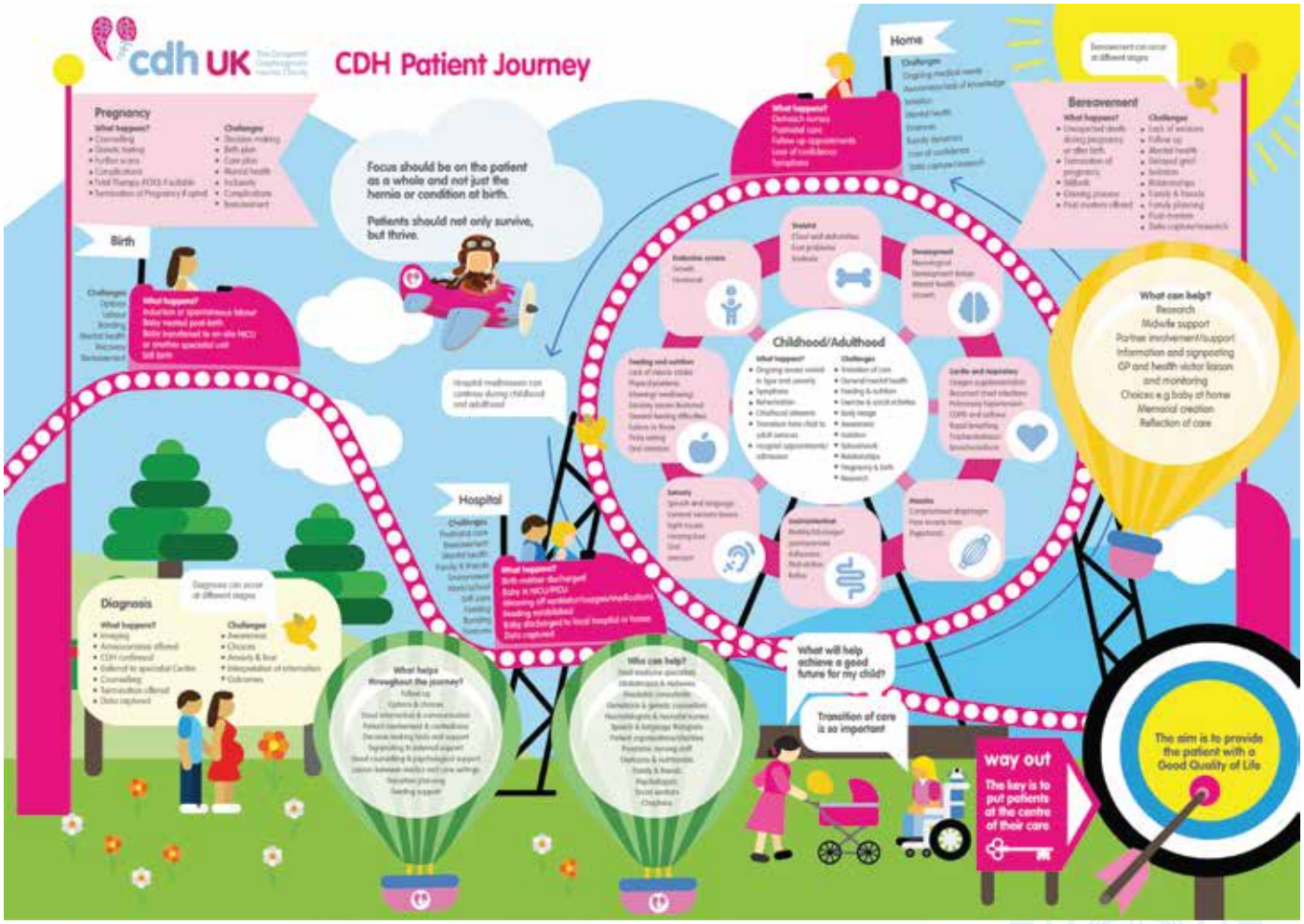
You can read about past, present and future projects that we have supported or funded on our website but here is a summary of what we have been up to in 2022.

CDH 2022

The main research event for us this year was the International CDH Meeting that is organised by the CDH Study Group and The CDH Euroconsortium and is attended by experts and healthcare professionals treating patients, from all over the world. This year it was hosted in Glasgow and main sponsored by CDH UK.

This event brings us up to date with what is going on in terms of research for CDH, enables us to listen to expert consensus opinions and informs us of any new treatments or guidelines.

We were very honoured to have been given the opportunity to present our work on developing the CDH Patient Journey, which has resulted in the production of a visual infographic. This has been a long and important piece of work that we hope will engage patients and healthcare professionals to use as a reference for management, care and further research. We hope that you like it!



CDH Research HUB

We heard about lots of exciting research going on and we will be providing more about this shortly, so please keep your eyes on our website and Social media channels.

The event also enables CDH UK to raise awareness of what our organisation is doing in terms of supporting patients, families and research and of any new resources. It is also an opportunity to introduce our volunteers to the event, which takes place every 2 years and to meet new and existing people who are involved in the care of CDH patients, or who are conducting research into CDH.

This is some of our team at our stand.

This is some of our team with Dr Neil Patel (Glasgow children's hospital).

Shown with researchers from the DHREAMS Research project in the United States who we have funded.

Here with researchers who we have funded from Leuven University Hospital.

The next meeting is in 2024 in France.

CDH Research HUB

cdh UK The Congenital Diaphragmatic Hernia Charity

New research funded

We also funded Neetje Crombag, a midwife from Belgium, who was working between London and Leuven to enable her to carry out research into patient reported outcomes following a prenatal diagnosis of CDH and we hope to see this work published in the near future.

Research Call Out

CDH UK is a leading Congenital Diaphragmatic Hernia Charity based in the UK. It is proud to have a dedicated CDH Research Fund that supports CDH research projects internationally. It has recently released a further £200,000 grant and is calling for expressions of interest.

Round 1 will open on 2nd January and close on 31st January 2023 and consists of a short application form to understand the research project Question and end points.

Round 2 will open on 1st February 2023 and will close on 28th February 2023 and consist of a further application to obtain full details of the research project including people and institutes involved, research design, required licenses, ethics and approvals for example.

Requirements

Applicants must be tenured with an academic/research institution.

Only applications for research that benefits Congenital Diaphragmatic Hernia will be considered. Applications that align with our research priorities will be highly favoured and are as follows:

- Cause and prevention of Isolated Congenital Diaphragmatic Hernia
- Improving survival rates with improved outcomes
- Improving outcomes and quality of life for patients and their families

Applications must include scientific and lay summaries.

Desirable

We would like to encourage UK based research or UK based Principal Investigators that are collaborating internationally.

We would like the research to begin within the next 12 months.

Considerations

We will also consider funding projects that involve other funders or that are part of a large research consortium requiring funding for investigators/ students for example.

We will consider applications for PhD projects.

Project length will be a consideration in decision making with a preference of under 5 years from start of project to delivery of results.

In the first instance please email.

Collaboration Ernica

Our membership with ERNICA - The European Reference Network for Inherited and rare Congenital Anomalies continues and on Wednesday 20 April – Friday 22 April 2022 the 6th ERNICA network meeting took place at the Biomedicum, University of Helsinki. New board members representing new ERNICA centres were welcomed by ERNICA coordinator René Wijnen. Other topics of discussion included; changes to the ERNICA governance structure, revisions to the ERNICA statute, ERNICA diseases and coverage, the ERNICA patient journey "umbrella concept", ERNICA financing and cross ERN initiatives.

The plenary programme was opened by René Wijnen (Coordinator ERNICA) and Mikko Pakarinen (hosting centre representative). René Wijnen introduced Steffen Husby (Gastroenterologist, Odense University Hospital) as a new ERNICA coordination team member and Paolo De Coppi (Pediatric Surgeon, on behalf of Bambino Gesù Children's Hospital Research Institute, Rome, Italy as Honorary Professor) and Laurent Storme (Pediatrician/ Neonatologist, CHRH Lille) as new co-leads of the malformations of the diaphragm working group (working alongside Jan Deprest (Fetal Surgeon/Gynecologist, UZ Leuven) and Beverley Power (Patient representative, CDH UK). The ERNICA overarching patient journey "umbrella concept" was introduced. René Wijnen presented the ERNICA patient journey as the overarching concept governing ERNICA activities. This was followed by a presentation by Nadine Teunissen (ERNICA registry project manager) on progress with the ERNICA/EPSA registry. The ERNICA/EPSA registry is developed as a clinical audit tool, with the primary aim of improving quality of care by benchmarking quality indicators. As chair of the ERNICA Scientific Committee, Roel Bakx then presented updates on the ERNICA research strategy 2022-2027, the ERNICA research overview and future funding possibilities. Two presentations were given on two research projects: 1. By Jan Deprest (virtually) on 'TOTAL-trial Antenatal intervention for isolated CDH. How do we proceed today?' The key note session on 'Transition' kicked off with a lecture from Silja Kosola, MD PhD, Adjunct Professor of Adolescent Medicine, Pediatric Research Center, Helsinki University Hospital and University of Helsinki on 'Transition: Critical considerations for getting it right'. Silja Kosola outlined the importance of a high-quality transition plan for patients following critical considerations (Clinical situation, age and developmental stage, life circumstances, move from transfer to transition, education of professionals, resources and contacts- CALMER). EPSA/ERNICA registry mirror working session. This session focused on sharing the first EPSA registry results with participating hospitals, to The ERNICA research strategy was discussed, in addition to funding opportunities, working group research priorities. Malformations of the Diaphragm / CDH working group session heard Beverley Power, patient representative CDH UK, discuss the patient journey drafted by CDH UK and patient engagement in alternative prenatal therapies. The core outcome set for perinatal intervention in CDH was presented by Simón Vergrote. The group discussed governance of the working group and cooperation with the CDH Euroconsortium. Lasty, future plans on a registry for FETO, the Smart tracheal occlusion trial and a planned training course for antenatal assessment were discussed.

The ERNICA Patient Journey as umbrella concept was introduced and the patient journey was presented by ERNICA coordination René Wijnen as the overarching concept governing ERNICA activities. Every ERNICA project addresses one of more stage of the 'Patient journey' which ensures they are relevant to the patient. The ERNICA coordination team will work with the disease specific working group leads to implement this concept. Priorities per working group The disease specific working groups met during this meeting in Helsinki to discuss various

Collaboration Ernica

activities and topics. Four research themes have previously been identified by ERNICA (The origin, impact, intervention and co morbidity in congenital/inherited rare diseases). The ERNICA scientific committee of which our Chairperson Beverley Power is a member, is working on an overall research strategy to facilitate and stimulate research collaboration between ERNICA members and partners. Please keep an eye on the ERNICA website for key network updates; https://ern-ernica.eu/

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Collaboration Baby Loss Awareness Alliance & UK Charity Week

Baby Loss Awareness Alliance

CDH UK was proud to be a member of the Baby Loss Awareness Alliance again this year and to support the #BLAW initiative during October. We both share the same awareness colours of pink and blue too!

Baby Loss Awareness Week

UK Charity Week

We were an official partner of UK Charity Week 5th-9th December again this year, raising awareness of the many great UK based charities supporting some amazing causes. It is another great opportunity to showcase our great work!

5th-9th Dec 2022
Celebrating 10 YEARS
#UKCharityWeek
What will you be doing?

cdh UK The Congenital Diaphragmatic Hernia Charity

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.

Archie McFarlane's Story

At 18 weeks we went for our anomaly scan, we were excited but also a little nervous just like most expectant parents. The sonographer went through all what she would be looking for throughout the scan. We started the scan and it took longer than expected, she was concerned about our babies heart. She spent a lot of time checking the valves then she told us that the heart was too far over to the right and we would be referred to fetal medicine and fetal cardiology in Belfast.

We attended these appointments but imaging was challenging due to positioning. We had a fetal echo which seemed to show good function of the heart the cardiologist said that this was great news. We couldn't help but disagree with this statement because why would it be shifted to the right? What would cause that?

The fetal medicine consultant suggested it could possibly be a CPAM or CDH, possibly even something else. We were offered a termination multiple times even though they could not confirm what was "wrong", it was then that we enquired about a private fetal MRI in Dublin as this was not an option available to us on the NHS in Belfast. The MRI was carried out at 27 weeks gestation in The National Maternity Hospital, Dublin and it was after that we were told our little boy had a left sided Congenital Diaphragmatic Hernia. His stomach, spleen, small and large bowel were up in his chest cavity, squashing his heart and lungs, one lung was only measuring 1.9cm cubed. We were told that our son's head to lung ratios were

Archie's CDH story (continued)

"good" but we were also told not to be too hopeful as sometimes a good ratio doesn't necessarily mean a good outcome. We were told it was a 50% chance our son would survive. We found the rest of the pregnancy difficult and kept our hearts guarded for most of it, not buying anything other than a pack of vests and a pack of baby grows with cars on them.. regardless, we promised our baby that we would be his biggest advocates. An induction was scheduled for 38+2 weeks though there was no NICU cot available on the day so I was examined and told to come back the following day to have my water's broken. When we arrived they did a controlled break of the waters as he was still too high up and 5 hours and 25 minutes later on the 13th of July 2022 he was born. Archie William. A " truly brave" "warrior". Archie was intubated at 2 minutes of life and whisked off to NICU to be stabilised. Archies blood gases showed high levels of CO_2 and so he was changed onto oscillatory ventilation to help with this, he was also on nitric oxide. Archie had a few very shaky days where it was unclear how he would do, one day they were going to send him to the mainland for ECMO but there was no transport team available due to staff shortages, thankfully this wasn't needed as Archie pulled through overnight. At 5 days old the decision was then made to transfer him to the PICU as it was right beside theatres and he was at the upper limits of the NICU ventilators due to his weight- 10lb 5oz.

Archie was transferred over to the children's hospital and it felt like a lifetime waiting to see him again. When he was 7 days old he had his surgery to repair the hernia. His surgery was a lot quicker than we expected, however the surgeon told us that he only just got away with not needing a patch, his hernia was significant. Archie continued to do well and the following day was switched to CPAP, his medications being continually reduced. However when he was 10 days old he was rushed

Archie's CDH story (continued)

back to theatre to fix a perforation in his bowel. His abdomen was full of meconium, requiring a washout and a 10cm bowel resection. This surgery proved difficult for Archie and he required blood transfusions and fluid resuscitation during it..
But our brave boy continued against the odds to do well. We finally got to hold him when he was 14 days old, it felt magical. Words can't describe how proud we were of our little boy. Over the next few days he was changed from CPAP to high flow oxygen then onto regular oxygen before he was transferred to the ward. On the ward we focused on feeding, Archie was able to tolerate 20mls orally and the rest via NG tube, we were trained on how to insert NG tubes in babies and how to use them.

Archie was discharged at 22 days of life. We removed his NG tube when he was 5 weeks old as he was able to breastfeed and take a bottle much better. However reflux was getting the better of him and we spent the night in our local hospital where Carobel was started in expressed milk for him. Archie has a hole in his heart, pulmonary hypertension and acid reflux but the only medication he is on is Omeprazole. He has had RSV and spent the night in hospital to monitor his oxygen levels, but other than that you wouldn't think he was any different to any other child. We are truly thankful to all the medical staff that played a part in Archie's diagnosis and care as well as to CDH UK for kindly providing us the new parent support pack and helping us as a family through a very challenging time. We have been extremely lucky with how our son has done given the statistics we were faced with, we are honoured to be his parents but humbled by this experience. We will make it our mission to fundraise and educate everyone we possibly can about CDH, the condition that touches 1 in 2500 families.

Chloe and Gareth Mcfarlane

Lorena's CDH story

Lorena Reign was born 10/12/21, 7lb 2oz in The Rosie Hospital. We knew she would be taken into NICU from birth after being diagnosed at the 20 week scan with CDH (Congenital Diaphragmatic Hernia) when I heard these words I had no idea what it was, or what it meant for her and her future. I had gone to the scan alone after having 3 healthy children, baby number 4 scan felt like a routine check. As soon as she was diagnosed I called my husband and he had googled it, within seconds and to put it simply told me "her organs are in the wrong place"

After this I was referred to many specialists and told a lot of information. The first specialist I saw took some measurements from the scan and told us your baby has a 20% chance of surviving.
I broke down...

The problem wasn't so much the hole, this was 'easily' fixed by surgeons. It was the fact her lungs had been squashed by her other abdomen organs which had entered the chest cavity through the hole in the diaphragm. I was told she would be taken straight away to be intubated and from there she would need to be stabilised and only when she was stable enough would she be able to have the surgery to fix the diaphragm. From birth Lorena came out fighting!! The delivery was perfect. I pulled her onto my chest heard her little cry and we had some skin to skin. Something I was told would not be possible due to her breathing but she was pink, crying and stable enough. From there she was taken to NICU and my husband went with her. I managed to go a couple of hours later. She was stable. The team were with her and my husband and I went downstairs for some sleep. A few hours later we went back and things had done downhill.
For the next few days Addenbrooks NICU did everything they possibly could to try and get Lorena better, she was holding on in there but she was maxed out on everything they could

possibly do for her. A consultant had been talking about ECMO to us since her birth and he was in talks with GOSH and Leicester hospital about an ECMO bed for Lorena. We knew from reading ECMO was the last resort and worst case scenario for her condition. Lorena then had a dip, she was telling us she was struggling. GOSH were then called to come and transfer her to get her near to an ECMO bed. They came and spent 4 hours trying to keep her stable enough for transfer. It wasn't possible. We then spent the next 24 hours waiting for the Leicester team, the longest 24 hours of my life. They were the only mobile ECMO team in the UK.
Finally they arrived. I ran up the stairs and met the consultant and I instantly felt at ease. ECMO comes with it's own risks and half of babies who go onto ECMO do not survive, It was a risk we had to take as there was no other way. The consultant was confident and he had faith in Lorena. He told us she had shown them signs of fight and that's why

Lorena's CDH story (continued)

they were there. To qualify for ECMO not only do you have to be a certain level of poorly, you also have to show signs of being able to make it. Our baby girl was fighting.

Finally she was in GOSH. When we arrived at GOSH they told us they would be 30 minutes getting her settled. I sat staring at the door for 4 hours until finally a nurse walked past and said "She's OK".

Lorena then spent 12 days on ECMO during this time there were complications, she had emergency procedures, blood clots in the circuit and everything that could arise as a problem arose. The flow stopped on the machine and the emergency procedure had to take place. The nurses and Doctors were simply amazing. She got through this and after we were told they had to do a brain scan due to the blood flow problem, if there's a problem with the flow it of course stops getting blood to her body including her brain. The scan came back clear. Everyone was astounded.

The day Lorena came off of ECMO it wasn't in the plan. They had clamped her off due to more complications and during this time she held her own. They decided to keep her off at this point due to the difficult time she had had on the circuit. The next 24 hours were crucial. But she kept going and kept strong! Lorena finally had her surgery on January 4th. Throughout surgery they told us she was rock solid. They told us she had no diaphragm at all on her left side, hence why she had been so poorly and the fact she had made it this far was incredible. Slowly day by day Lorena was getting stronger and she was transferred back to Cambridge on January 16th.

After this Lorena flew through milestones and was finally extubated on January 24th.

It was confirmed by x-ray before discharge Lorena had an unsafe swallow and we would have to take oral feeds extremely slowly. Lorena spent a further 3 months in hospital and was initially discharged feeding part orally and 50% NG feeds in March 2022.

We excitedly brought her home to meet her siblings for the first time! It was a Wednesday, only to be back in A&E on the Friday with an increased respiratory rate. When initially discharged I was not told all of the signs to look out for. I just knew she wasn't right.

For the next 2 months we spent every other week in hospital. With suspected aspiration or a viral infection. On average the stays lasted for 5/6 days. To say it was a struggle is an understatement. I worried so much she would deteriorate to the place she was when she was born. She was far from it but it was a very unsure and scary time. Plus trying to be there for my 3 other young children at home, I felt awful not being around. Each time she was admitted she was treated with antibiotics and oxygen, then we were sent home being told she would get stronger and it would get easier.

Finally after a particularly long stay in May the respiratory consultants contacted Lorena's initial surgeon in GOSH and they decided it was time to keep her in hospital until she was strong enough for another surgery in June - a PegJ insertion. Her reflux was so severe (as at this point she was having nothing orally) milk was coming back up and going into her lung, causing her recurring chest infections. In the midst of all this, Lorena was the happiest bunny.

She smiled through it all!

Lorena's CDH story (continued)

Finally July 27th came. We had been taken from Addenbrookes a few days before surgery to get Lorena ready and do all the necessary checks. It felt very strange going back to GOSH. When we left the first time Lorena had still been intubated and it was Christmas, this time Lorena was in a much stronger position and it was the summertime. After describing all of Lorena's symptoms to her surgeon over the phone her surgeon was shocked at how well she was doing; CDH babies are so amazing & resilient! She was thriving in a way no one expected. There was a high possibility Lorena may have to stay intubated and go to intensive care after her operation, but this was not the case. She was blowing us all away. After her procedure she was unsettled for a few days and then back to her happy self. She was and still is being fed into her jejunum (past the stomach and into part of the small intestine) as this means there is nothing in her tummy to come back up and get into her lungs. Her surgeon informed us the reason her reflux is so severe is because her defect was so bad, she had nearly no diaphragm on the left side and the natural diaphragm supports with keeping things down so she had suspected this would be the case.

Our beautiful, miracle lady has been home now since this operation in July!! Not without ups and downs. Numerous GP visits, she is on overnight oxygen, daily medications and of course her feeding pump 16 hours a day. But all we hope for is her to be happy and she smiles all day every day! She's clapping, waving, calling mama and my heart melts every time I hear her voice calling out for me. CDH babies are just so fragile, I remember even the slightest movement could cause Lorena to deteriorate due to everything being in the wrong place. It was just horrendous how bad it was. But she is now

shining so bright and we just cannot believe how far she's come! The worry and heartache was so worth it and I'd do it all over again in a second.
She deserved a chance and I'm just so glad through all the negative possibilities that were told to us, we as parents gave her that chance.
She lights up our lives.

Frederick's CDH story

My son Frederick Paul Boyd was diagnosed with LCDH when I was 18 weeks pregnant. It was classed as moderate-severe, with a 20% chance of survival. His LHR was 26%. I underwent FETO (Fetoscopic Endoluminal Tracheal Occlusion) surgery to help Freddy's chances of survival at 29 weeks pregnant.
The balloon was removed when I was 34 weeks pregnant. Freddy's LHR went up to 46%, which was amazing.

My water's broke when I was 34+5 weeks pregnant and I gave birth to Freddy 2 days later, on the 19th April 2022.

When Freddy was born, he did not cry. I had a cuddle with him before they cut the umbilical cord. He was swiftly taken to be cleaned up and to be placed on a ventilator in the neonatal unit. I went to see him when I was able, and he was beautiful. The most beautiful baby I had ever seen. He had lots of wires and tubes helping him to survive. He unfortunately was struggling. We found out pretty much everything was up, including his liver.

Freddy was on 100% oxygen to help in breathe. The first day in the neonatal unit was full of ups and downs. His oxygen/saturation was sitting around 70/80%. We neede him to be at 90%+ to be able to even think about performing the hernia repair surgery. Freddy's oxygen/saturation continued to fall until we had to say our goodbyes on the 21st April 2022.

He passed away peacefully in mummy's arms, with daddy also by his side.

We miss him every day.

Leonidas's CDH story

On Leonidas's 20 week scan we found out he had CDH. Initially we didn't know what it was or what to do. The consultant who diagnosed him wasn't very optimistic and gave us all sorts of negative outcomes.

Leonidas was under the care of professor Kipros Nicolaides and his team at Harris Birth Centre.

We returned on the 26th week to see the true extent of his issue. We had a meeting with professor who told us about his new feto trial with moderate to severe CDH babies. For us we knew this was the right thing to do and we went ahead there and then. The initial process went great and we were out of there within an hour! We were scheduled for fortnightly scans to see how things progressed.

At his first scan we were amazed his lung had grown from around 32% lhr to above 50! We were estatic. On his second scan his LHR had dropped down to near enough where we started, so we were scheduled for a scan a week later with professor. This is where we discovered the feto balloon had deflated and we were back to square one. So we opted to go again and remove the old balloon and put a new one. After a couple painstaking hours this was complete.

On 33 weeks his mum's waters broke and was rushed to kings college hospital. This was a major issue and the feto balloon was in his throat meaning he couldn't breathe if he was born. Kings Maternity Unit wouldn't discharge her incase she went into labour, and the professor couldn't do his removal surgery without being in his centre. It took around 12 hours but once the logistics were figured out she went to the professor for removal surgery. This in itself was an issue as the waters had broken and took much longer than usual.

Leonidas's CDH story (continued)

Back in the maternity unit pregnancy slowed down, so by day 4 they were willing to discharge mum home, however she and the baby both took a turn and they opted for an emergency c-section.

Leonidas was born naturally (without c-section) on a theatre table at 15.30 on 28/04/22 weighing 5lbs 6. He was ventilated within 1 minute and was allowed a brief moment of skin to skin with his mum.

This is where his Nicu journey began.

He was ventilated and put on sleeping drugs and antibiotic from birth. On day 5 he had his surgery, which took around 4-5 hours. He had a very large hole and minimal diaphragm so they stitched together what they could, and stitched a animal skin patch to his rib cage. He was then taken back to Nicu until he was 10 days old.

On day 10 he was transferred to HDU where we finally got to hold him. He was off his ventilator and graduated to a different breathing machine.

He kept going from strength to strength and lowering oxygen and pressure.

On day 20 he was transferred to Scibu at King's College, being on only minimal oxygen threw a canula.

We were then transferred to our local hospital to establish feeding.

On day 35 after 2 sleep tests we were finally discharged home!

We went home on 2 different reflux meds and vitamins. He came off all of these by 4/5 months old and is now establishing eating food. We have regular check ups with our surgeon and consultants, but Leonidas is doing great.

He has been on holiday (after doing a oxygen depravation test), he goes swimming every week and sensory. Looking at him nobody would ever tell.

He is a warrior!

Noah's CDH story

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

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

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

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

Then the news they had been waiting for, for so long, Alexis was pregnant and she and Gary were to be parents, we were so happy. On the day of the 12-week scan, I was in work and I received a call from Alexis, she was sobbing inconsolably. Alexis had had a missed miscarriage and their baby had died.

Alexis and Gary would never forget their baby, now a star in heaven with nanny Avril Scott, looking down on us.

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

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

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

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

Noah's CDH story (continued)

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

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

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

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

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

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

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

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

Noah was born at 11.53pm on Wednesday 26th May weighing in at 6 lb: 13 1/2oz, Alexis and Gary were not allowed to hold their baby, but the staff did allow him to be placed on Alexis's chest for a few seconds.

Then the doctors then began to treat him, they started by intubating Noah but could not get the first tube in, it was too big, we all kept looking at each other shocked, trying not to panic, the second tube was inserted within a minute, it seemed like hours, I dared not breathe as I didn't want to show Alexis how worried I really was. Successfully intubated, Noah was attached to the life saving ECMO machine and taken to ITU. Alexis and Gary were now alone without their baby.

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

At 10.30am on Thursday 27th May 2010, a time and date I will never forget, I was in my car when my mobile rang, I answered it immediately, Gary told me that Noah stopped breathing at 10am, he had been resuscitated but the hospital doctors were advising to have him baptised just in

Noah's CDH story (continued)

case it happened again and they couldn't bring him back as he was a "very poorly little boy". He asked me to come to the hospital with my husband Tony and daughter Cara, as the baptism would take place at 5.00pm.

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

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

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

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

Noah had won his third fight for survival.

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

Baby Blues

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

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

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

Noah's CDH story (continued)

The care in ITU was second to none; they were supportive, allowing friends and family to visit Noah. Noah had been ventilated from birth and on the 10th of June he was extubated and put on c-pap, which he removed himself after 1 hour and started to breathe unaided. It was also the day Alexis and Gary held Noah for the first time.

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

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

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

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

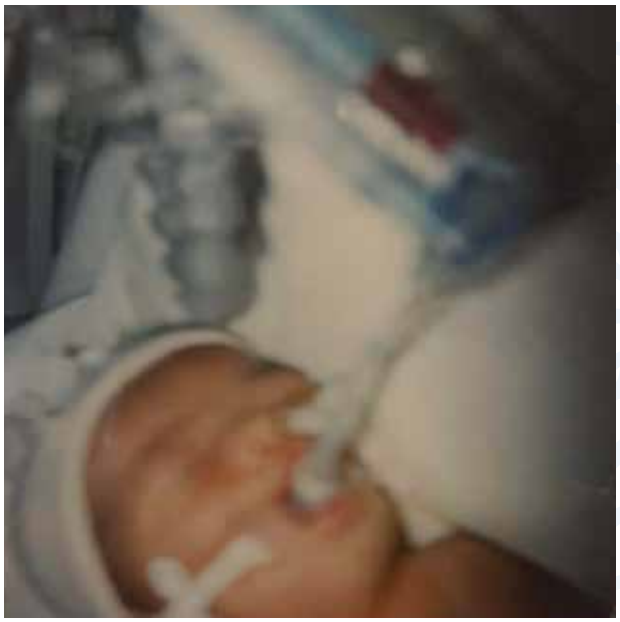
Noah is now sixteen months old, he still has problems eating and drinking and is fed through a tube, but we can now cope with that because he is alive, he is a bubbly happy little boy with lots of love to give. His CDH has made Alexis and Gary into the strong couple they are today and in August 2011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

Freyah's CDH story

Our Freyah was diagnosed a day after birth with right sided Cdh and after a hectic hunt for a nicu bed she was transferred to have her operation at John Radcliffe hospital in Oxford. She unfortunately reherniated last year and had her repair operation at our local Children's hospital in Bristol. This time she needed a gortex patch repair. Since then we have been still trying to find a way forward to help her gain/maintain weight and having little stamina/easily fatigued. After a bit of medical head scratching, twoing & froing and a few tests - a cardiac mri this year showed she has little in the way of a vascular system in her right (hypoplastic). This explains these issues and why she's prone to respiratory infections. As parents we are always looking for better ways to help support her with this and only spoke to a respiratory physio today. We've learnt so much!

The CDH UK helpline was also able to give us some advice this year about some of her care needs - it's reassuring to have this available as advice about CDH complications can sometimes be conflicting from other sources. As she is due to start school in September we've managed to secure her an ehcp. She is also on the list for a PEG procedure if we can't get her weight up. However despite any setbacks she us still a happy, inquisitive, sociable (and sometimes cheeky) little girl who loves preschool.

Anuska's CDH story



My daughter was born with Left sided Diaphragmatic Hernia at Queen Charlotte Hospital in Hammersmith on the 21st September 2004. Anuska had a surgery to repair hernia at 6 days old and remained in NICU for 21 days. Back in those days, we were not aware of CDH at all and did not know what to expect. We were given 50/50 chance at the time. She is so confident showing her scars and bless her, has been extremely active playing hockey, netball and attends gym regularly.

She underwent another major surgery at Leeds Hospital in 2010 due to blockage caused by scar tissue.

She is currently studying at Queen Ethelburgas Collegiate in York . She is doing her A levels and aims to be an Obstetrician and working extremely hard. Her aim has always been that she wanted to give back to the community.

She has achieved so much. Her GCSE results were brilliant. She is now a college ambassador, does mentoring and is a Prefect in the boarding school. She has done volunteering in Frimley Park Hospital and York Hospital, also works in the nursery with small children when she has half term holiday.

As this is a milestone in her life celebrating turning 18 years in 2022, we are extremely proud of her. My husband is a serving soldier in the army and I am a registered nurse working in the NHS.

A chat with Tracy Benson

our Fundraising Merchandise Co-Ordinator

Tracy Benson is our Fundraising Pack Co-ordinator and she works closely with Sarah Jones our Fundraising Administrator and the CDH UK Committee. Our Volunteers are extremely important to us and we love to celebrate them during Volunteer week which takes place during the first week of June and coincides with CDH Awareness Month. We took some time out to find out more about Tracy's role.....

Q **What does your role involve?**
I send out the fundraising items that people request when they organise an event.

Q **How long have you volunteered for CDH UK?**
I have volunteered nearly 11 years now.

Q **How did you get involved with the charity?**
After being diagnosed with my first daughter I found CDH uk on Google and Facebook they were so supportive for us and I wanted to give something back.

Q **What do you like best about your role?**
I like feeling I am helping others that have been touched by CDH.

Q **What advice would you give to others who are thinking of volunteering?**
It's very rewarding and doesn't take up too much time.

Q **What advice do you have for anyone wanting to fundraise for CDH UK?**
Fundraising is so vital for us every bit helps so please consider it.

Q **What are quick and easy ways to fundraise for CDH UK?**
Bake sale is a nice easy one and who doesn't love cake!

Q **How does the charity thank people for fundraising for the charity?**
You get a certificate and a mention in the Facebook page if you want it.

Q **Name something you have learned about CDH UK since joining the team?**
The medical research side was a surprise to me! I didn't realise we did so much for that!

Thanks Tracy for giving us an insight into your role and for all that you do for CDH UK!

Here is a lovely picture of Tracy with her family.

Our Fundraising CDHeroes!

ALFIE HOLMES

Fund Raising for Halloween

Alfie Holmes raised **£190** this Halloween by holding a sweet fundraiser.

Alfie filled a glass pumpkin jar and his friends and family donated £2 for a guess at how many sweets were inside.

Our Fundraising CDHeroes!

Mum Becka
Fund Raising in memory her daughter Dakota.

When it comes to fundraising we can always count on our families to come up with some amazing fundraising ideas, just like Becka did in memory of her daughter Dakota.

Becka organised Christmas lights on her house and a snow machine plus dressing up as Santa and doing horse and cart rides.

Becka tells us she is still counting the donations, but that she has raised a great amount so far!

Well done Becka and thank you to everyone who supported her!

Ho Ho Hope Santa and his reindeer enjoyed it too!

Our 2022 Get Together

We were over the moon to be able to host our first get togethers since the pandemic ended and they were held in Glasgow and Gulliver's Land in Milton Keynes.

Our get togethers are a great way to bring familiestogether for support and friendship and we try to hold at least one each year. We are already thinking about where to host the next one in 2023 so keep checking in on our social media and website for updates.

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Awareness 2022

Our Awareness month in June saw families joining in with events and building light ups to draw attention to Congenital Diaphragmatic Hernia.

We use our hashtag #joininjune4cdh to help to encourage members of the public to join in too.

It is really important to support this awareness initiative as it not only highlights the condition to the public and healthcare providers but also highlights any ongoing issues for patients and families including bereavement needs.

Our light up initiative 'Colours 4 CDH' saw various landmark buildings light up pink and blue for awareness month.

This is Newport Civic Centre one of the landmarks that supported the initiative.

We also had an organised event called Jubilee 'Jog 4 CDH' whereby participants paid an entry fee and then set up their own fundraising page through our platform hosted by enthuse and received a commemorative limited edition jubilee medal.

Finally, we also encouraged people to take part in our 'CDH Knitathon' to knit our CDHuggy bears using a free pattern and then selling them for a donation to CDH UK.

We would like to thank everyone who joined in 'June 4 CDH' and supported our cause!

Details of our 2023 awareness month activities will be released in the new year and announced on our website and social media.

Impact Statement

We like to reflect on what impact we have made and so every year we look back on our last year (in this case 2021) and create a quick infographic for you to quick glance at what your donations have helped us to achieve!

2021

Impact review

cdh UK The Congenital Diaphragmatic Hernia Charity

Making a difference

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!

OVER £650,000

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 2022 and contribute even more!

3328

HOURS

Is the minimum hours worked by our volunteers to provide services and resources to support families and research this year

6

AND MORE TO COME

We supported six research projects representing the patient perspective, provision of information, recruitment of patients, sharing of results, patient safety, ethics, reviews and writing plus other help

MORE THAN £40,000

IN CHARITABLE SUPPORT

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.

100'S

SUPPORT PACKS, INFORMATION BOOKLETS & MEMORY BOXES

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

What will you do to support us?

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

How will you help us to improve outcomes?

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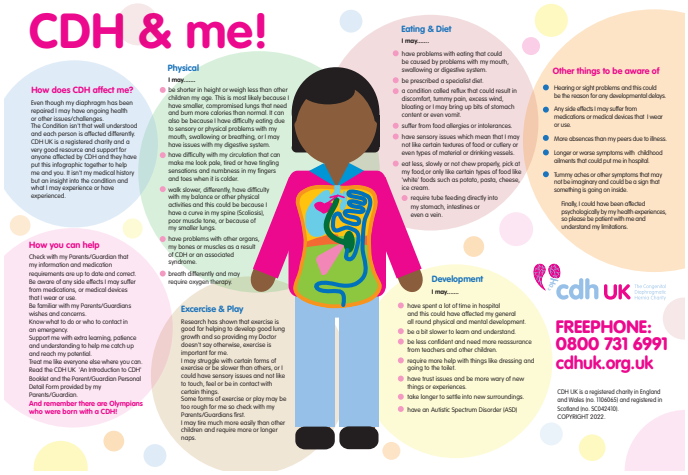
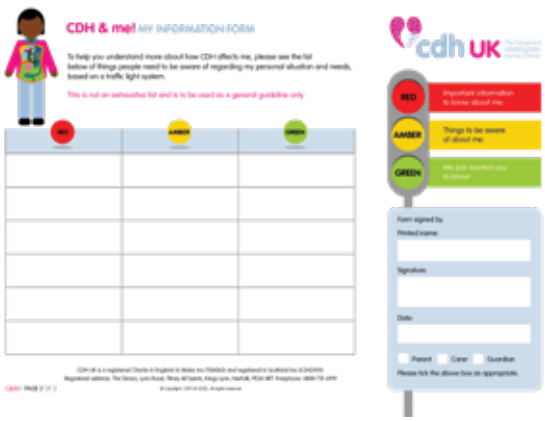
Impact Statement (continued)

We are the first CDH charity to develop the CDH patient journey from the patient perspective that we hope will have a huge impact on future care and outcomes. You can view the infographic in the research hub section and we would love to hear your feedback on this for future improvement. You can email your feedback to info@cdhuk.org.uk



We have also developed a CDH and Feeding booklet that will become available in the new year. We hope this will be a great resource for parents and patients.

We have developed a new patient information pack for carers that is available for download on our website. This pack we hope will help to raise awareness and give important information on any additional needs. It is ideal for starting nursery or school.



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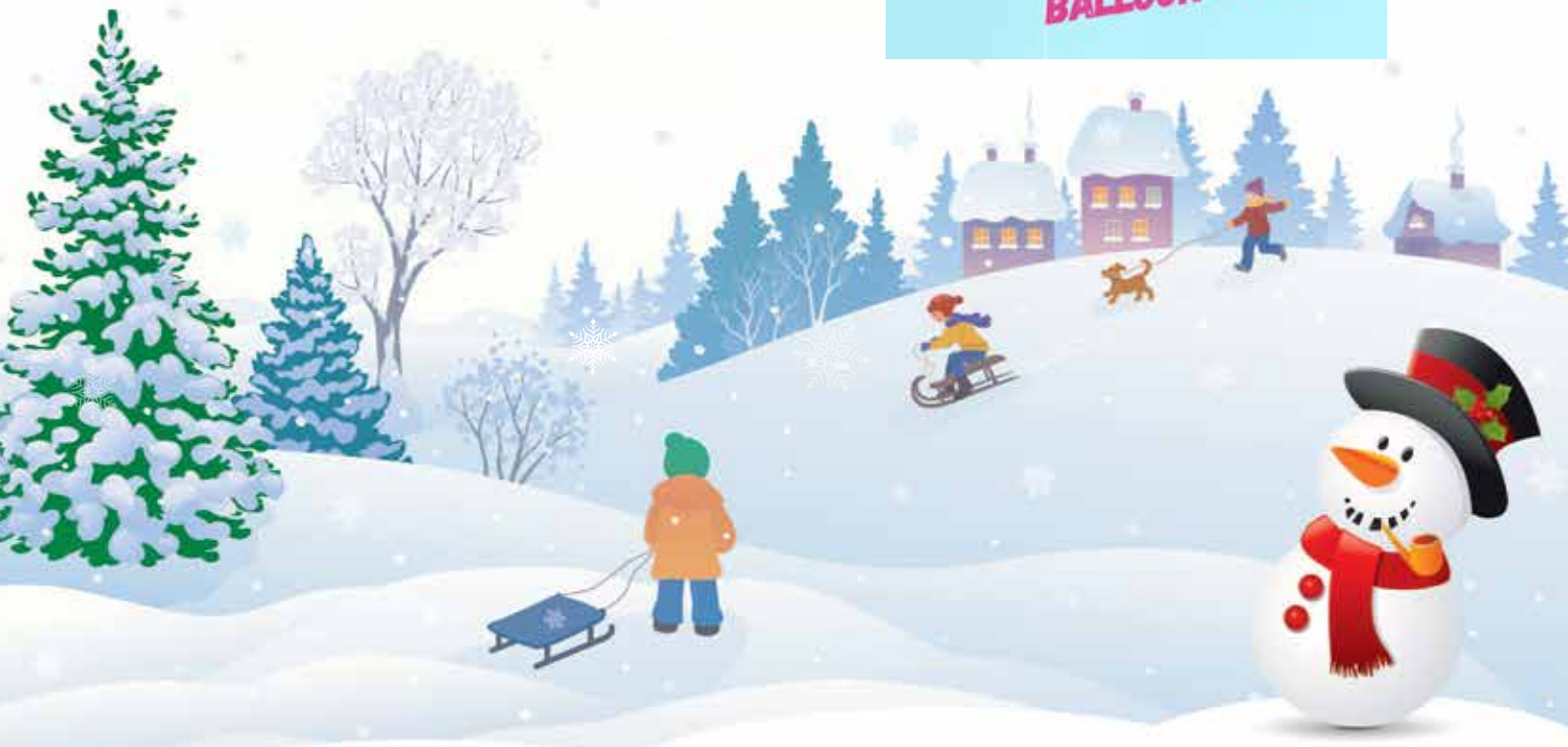
2022 Snowflake Appeal

Our annual snowflake appeal takes place each year starting on the first of December. The aim of the appeal is to grow our Research fund with the donations received.

This year we decided that instead of commissioning a new tree snowflake, we would offer our late Queen's limited edition Jubilee medal in return for a £5 donation. These will make an excellent keepsake, but we have limited availability and once they are gone, they are gone! You can find the on our eBay shop.

We are also running a virtual Christmas Cracker Virtual Balloon Race with a first prize of a luxury hamper (includes alcohol and nuts) and 2nd prize of an Amazon Echo Dot. You can enter through the link that you will find on our social media channels and the race link on our website.



Autumn Anxiety and Winter Woes

Autumn and Winter can bring lots of fun; Halloween, bonfire night and snow, but for CDH patients and families, it can also bring stress and anxiety.

Autumn and Winter see viruses and other illnesses spreading around and so It is understandable that parents worry about their child picking up something and especially if they have ongoing lung or gastric issues. It is also particularly concerning for parents going through their first Winter. However, thankfully most children experience nothing more than perhaps a few more days of symptoms than the average child and there are also things you can do to help lessen the stress.

We have put together an easy reference infographic and provided some of our tips and advice below, which we hope will help over the coming months and prepare you for next autumn and winter.

1. Speak with your Consultant, specialist nurse, or your GP initially to discuss any concerns and to see whether there are any management options available; such as prophylactic antibiotics for recurrent chest infections. This is a long term, small dose antibiotic course that may be helpful. Remember though that this management treatment is not offered as a standard treatment and may not be suitable in your case. We also can offer support via our **freephone support line 0800 731 6991** or our group forums.

2. Make sure vaccinations are up to date and chat with your GP, Practice nurse or Health Visitor if you have any concerns around vaccinations or need further information.

3. Check your prescribed and home remedies medicines to make sure you have plenty in for the virus season. Things like inhalers, rehydration sachets, cold remedies and pain medications, chest rubs and sprays etc. Plug in aromas (menthol) can help ease symptoms and for older children and adults steam bowls with drops of menthol can help.

4. Practice good personal and home hygiene to prevent passing on viruses to others. We all learned how proper hand washing helps to stop viruses spreading during the covid pandemic, so continue with this great prevention tool!

5. Do not be afraid to ask family and friends to refrain from visiting if they are unwell (this works both ways!) and remember that they can also be of great help in running errands for you if you, or a member of your family are unwell. You can also ask your Child's carer such as nursery or school for a chat to let them know of any concerns and to plan ahead together. It may be that you can discuss home schooling options during outbreaks, or how to recognise when your child is unwell.

We also have a CDH & Me infographic that you can let your child's carer know about your concerns around Winter illnesses and this can be downloaded from our website under 'useful resources'.

Finally, if you feel that your child does need further treatment don't delay in contacting your GP or the NHS 111 helpline. In a real emergency use open ward access or A&E. Please remember though that most viruses are self-limiting and rarely cause major problems in children with CDH, but if in doubt check it out!

Autumn Anxiety and Winter Woes

Colour in the Christmas Tree & Presents

CDH UK

Christmas Trimmings Word Search

holly
mistletoe
baubles
tinsel
candle
lights
presents
angel
star
stockings
wreaths
bells

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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.cdhuk/enthuse.com/profile

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@CDHUK_CHARITY

FIND US ON FACEBOOK

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