CONUC The Congenital Diaphragmatic Hernia Charity

Hello Readers,

I have been invited to guest edit this year's Christmas newsletter and I have to say that it doesn't seem two minutes ago that I was helping with last year's newsletter!

For those of you who don't recognise me from my photo, I am Beverley Power and I am a Trustee and Secretary for the charity and this year, following study in Barcelona, I became the Research and Development Officer for CDH UK, as I am now considered a patient expert in this field following my Summer School studies and certification. This means that on behalf of CDH UK I am participating in some very exciting projects and as you will read in the newsletter I have been very busy respresenting CDH UK in this area already this year.

I first became involved as a volunteer in 2009 when my Daughter was pregnant for the first time with my Grandson, who very sadly died from an isolated Bochdalek (left sided) CDH at just 8 days old in December 2009. I have volunteered ever since and now work pretty much full time for the charity.

I really enjoy helping others and the challenges that the work brings. I love to explore new and innovative ways of building on our collaborations and our Research Fund. This year for example I helped to set up IDEA, which is an alliance for CDH and other abdominal wall anomalies organisations, which operates on a global level, so that we can all work together for better outcomes for patients everywhere. This will run completely independently of CDH UK, but the charity will mentor the project for the first couple of years until it finds it's feet so to speak. IDEA was brought about because of our work within the European Network ERNICA, for which we are a founding patient organisation. I am also excited to announce that CDH UK will be an official partner of World Birth Defect Day (#WBDD) which takes place on March 3rd 2019.

Whatever time I have to myself I like to spend with my family, travel and practice Yoga and I am currently training to become a Yoga Teacher.

So, that is a little about what I do and what some of your donations help us to acheive. I am really looking forward to seeing what 2019 brings and I would like to say a huge thank you to you and my colleagues for the continued support.

I hope you enjoy reading this year's newsletter as much as I have enjoyed editing it.

Wishing you and your families the warmest of Season's greetings and a happy and healthy New Year!

Here's to 2019!

Welcome to our Christmas 2018 newsletter!



Beverley Power

Research feature

CDH UK funds vital research into CDH.

In 2017 CDH UK funded £500,000 worth of CDH Research projects. Over the past twelve months we have received updates from all four projects, which are going according to protocol with the exception of two projects, one of which is currently undergoing a protocol amendment and one has been granted an extension to the study duration, which has resulted in some additional results.

We are currently working on our own project to develop a mobile application for CDH patients and we hope to see this inch forward another stage in 2019.

CDH HAS DONATED **£500.000**

We are now heading towards our 1 million mark for research funds and we would love to see you supporting our efforts again in 2019.

DISCLAIMER:

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The information in this newsletter is not to be substituted for medical advice. Every child is different and you cannot compare the progress of another child with CDH to the progress of your own child.

Research

Awareness Day

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June is CDH Awareness month and 28th June Awareness day. This year we ran a National Radio Campaign inviting families to be interviewed by local radio stations up and down the UK.

Beverley our Secretary and Research & Development Officer and one of our Patrons; Professor Paolo De Coppi, spent a half day at recording studios in London giving interviews to radio stations including the BBC.

The campaign was a great success and we would like to thank all those who took part and listened in on the day. You can listen to our podcast made on the day on Podbean (CDH UK) and on our You Tube channel.





DISCLAIMER:

Leuven University visit

CDH UK was very honoured to be invited to the world renowned Leuven University to witness the thesis and defense of PhD student Maria Russo, along with other eminent Clinicians who have an interest in CDH. CDH UK helped to fund Dr Russo's thesis entitled 'Prenatal intervention to reverse pulmonary vascular changes induced by Congenital Diaphragmatic Hernia', it was accepted and her Doctorate awarded.

Dr Mario Russo is a great supporter of CDH UK and so we were very glad to be there for her defense. Her thesis abstract is available on our website to read.

We were also privileged to be invited to witness the removal of a FETO balloon from the trachea of a baby still in the womb. This was a very informative and interesting procedure to witness and it will help greatly when counselling parents in the future. We wish the family all the very best when their baby in born.





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Our Charity Ball came back with a bang to Birmingham this year with the help of the Broadmore-Johnson family. Jade's Daughter Aaraya was born with CDH and so she was very keen to help organise this major fundraising event that helped to raise £7,000 for CDH UK.

The evening was a huge success and guests were treated to live music from Britain's Got Talent star Pippa Langhorne, a table Magician, Dancing Vegas Showgirls and our Fun Casino.





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We would like to thank all of our guests, volunteers and especially Jade Johnson and her family for a really enjoyable evening of fundraising.

If you are interested in helping out with our next major fundraising event in 2020 please email volunteer@cdhuk.org.uk

DISCLAIMER:

CDH Stories

Rebecca Joanne Wilkinson's CDH story



From the moment I found out I was pregnant I always felt there was a black cloud hanging over me. We had our 12 week scan and I thought it would put my mind at rest, it didn't. Then we went for our 20 week scan and I can remember very vividly our appointment being rather late and my husband commenting on this. My reply was that anything could have happened to a lovely couple and their baby, that this could be why they were running behind and how would we feel if we were the reason someone's appointment was late. So off we went into our scan where a young male training began my scan, I could tell he wasn't sure on something and then a fully trained lady continued, from then I just knew something was wrong. When the scan was over she was telling us all that was well with our baby and then she told us that our babies stomach was in her chest which would indicate there was a hole in the diaphragm. I was confused, I didn't understand but it sounded horrific. We were taken to a 'quiet room' where we waited for another lady. We sat in silence, tears streaming and holding one an other. The lady came in and she was lovely, she explained what they thought it was but that we would need to go to a specialist hospital to have it confirmed. We were devastated as were the whole of our families.

DISCLAIMER:



Rebecca Joanne Wilkinson's CDH story (continued)

We went for a scan at Queens Medical Centre and it was confirmed our baby had a left sided congenital diaphragmatic hernia. We then decided it was appropriate to find out the sex but baby was playing hard ball and we couldn't see. We had to have a very tough conversation about whether or not we wanted to continue out pregnancy as the harsh reality was Baby was given less than the average 50/50% survival but for us as a family there wasn't any way we weren't going to give our baby a chance. We were allowed to go for another scan just to find out the sex, we had one feisty and beautiful girl on the way. For myself it was bitter sweet as I had a little boy and I'd always wanted a little girl so the thought of the reality that we could lose her hurt to say the least. From that moment our baby had an identity and we named her Rebecca Joanne Wilkinson.

Rebecca began to show her personality and filled me with joy and hope with her feistiness. Through friends, a local church found out about our story and asked if they could pray for us and Rebecca. I felt a sigh of relief, I could allow myself to cry and feel sad knowing that other people had her back by praying for her. They gave me this piece of material known as a healing cloth. I placed it over my stomach each and every night.

The end of my pregnancy wasn't the most pleasant, Rebecca again was showing off her personality but had me worried.

The day came for Rebecca to enter the world with the help of some amazing midwifes and doctors. She let out two cries which felt amazing knowing she was trying to breath for herself but scared us as we knew she wasn't supposed to. I got to say hello and make sure she had her healing cloth with her before she was taken to the neonatal unit. The wait to see our daughter felt cruel but we knew she was in safe hands. My husband wheeled me down so we could meet her properly. She was beautiful and was doing extremely well considering.

The following day was hard, at first felt I couldn't touch her but the fantastic nurse caring for Rebecca along with my husband put me at ease and I just sat with my hand with hers. Rebecca was strong enough to have her surgery at 3 days old! She did so well. Rebecca went from strength to strength and just over a week old she was moved to a children's surgical ward. We were getting closer to coming home.

We had a blip with her feeding but eventually got to the bottom of it and at 3 weeks and 4 days old she was able to come home! I don't even know how she managed it so quickly. This was exciting but our nerves were shot.



Rebecca always had her healing cloth with her, it went with her for her surgery and it stayed in her bed with her. A few days after her surgery Rebecca was sick, her sheets were changed and from then the cloth was lost. I was heartbroken as I wanted to keep this for Rebecca and explain what a beautiful church and beautiful people did for her. But I decided that the cloth was lost for a reason, it had left Rebecca as she no longer needed it and there were more sick babies that were in need of it.

Rebecca was finally able to start building a relationship with her older brother, she now absolutely idolises Harry, even when he is tormenting her. Little does he know that when she can she will rule the roost and get her own back.

Me and my husband had a pipe dream of living in Cornwall and if anything good has come from going though what we have with Rebecca it's that life is too short and to reach for the stars. Myself, my husband, Harry and Rebecca are now living in Cornwall living our dream.

DISCLAIMER:

Joshua Topping's CDH story



As we arrived at the hospital for our planned induction my husband Mark and I felt nothing but excitement. We were finally ready to have our third baby, a boy. We had two daughters aged 8 and 5 and our unborn baby boy would make our family complete. I was 38+6 weeks. The induction was straightforward enough as was the labour. Only two real hours of pain, a couple of pushes and our beautiful baby son, Joshua Mark Topping, was born at 10.01am. When he was delivered there was no initial cry, just a grunting noise. He was swiftly taken to the resuscitation bed and given oxygen. The room filled with paediatric staff. There was still no cry. Despite this I was reassured that it was mucus on his lungs and he needed some support in NICU to get rid of the mucus. There was no indication that there was anything seriously wrong. We were obviously concerned but all the medical assured us that Joshua would be fine.

When we got around to the NICU, Joshua was in obvious distress and was finding it difficult to breathe. The nurse explained that he would require an x-ray at 4 hours old to rule out anything serious. It would be the result of this x-ray that would see our world shatter around us. The x-ray diagnosed Joshua with a left-sided CDH. The nurse broke the news to me and all I could do was cry. She told me they were going to incubate him and he was being transferred to a specialist NNU in Belfast where he would await surgery.

The next few hours my husband and I were in a state of utter despair. Thoughts ran through my mind; is my baby going to die? Is there something else wrong? Is he going to need a new heart? Our parents were heartbroken for us. We felt completely helpless. The transport team arrived to transport little Joshua to the Royal Maternity Hospital Belfast where he would be admitted to ICU in the neo-natal department. It was one of the most heart-breaking moments of my life; my new-born baby, 8 hours old, being taken away in an ambulance whilst I stood there utterly helpless. We followed in the car to the hospital and it would be some hours before we would be reunited with Joshua. At 11pm that evening we were taken into the Intensive Care ward of neo-natal. Joshua was hooked up to so many machines it was difficult to comprehend. A consultant then sat us down and explained what would happen in the coming days. She told us about CDH, how it had between 7-10 weeks gestation, what was happening inside Joshua's little body and how the surgery would be performed. This explanation helped us to begin to realise, to some degree, that perhaps Joshua would make through this most critical stage.

DISCLAIMER:

Joshua Topping's CDH story (continued)

The following days were a mix of sheer exhaustion, both mentally and physically. We had to break the news to our daughters about Joshua which was extremely difficult. They spoke about their baby brother with familiarity despite not having met him. We discovered that in fact 50% of babies with CDH don't make it and we began to see the light at the end of the tunnel for Joshua and our family.

The day of Joshua's surgery was one of the hardest we had to endure. Physically shaking and trying not to be sick or faint I signed the consent for surgery for my 4-day old baby boy. We were talked through the procedure, and of course the possible outcomes both good and bad. All you can do in a situation like that is to put your trust in the medical staff and pray. Seeing Joshua prepped for surgery was dreadful. He was heavily sedated, with central lines placed in his body including his head. All I wanted to do was to take his place. The next four hours passed slowly. Finally, Joshua's surgeon came to find us and told us his surgery had gone well. She said the hole had been large but she was able to repair it without mesh. The relief we felt as that moment is indescribable. Our little fighter had made it through the surgery. Over the next few days Joshua continued to progress well. At one week old I finally got to hold my baby boy as he was off the ventilator. It was the most amazing moment, a moment that I had been wishing for from the second he was born. My baby in my arms where he belonged. Unfortunately, his recovery took a setback as at 9 days old he contracted sepsis and was incubated again. This was another very worrying time but thankfully the medical staff caught it quickly and he was treated with antibiotics and this helped to avert a critical episode.

From then on Joshua continued to fight and miraculously we were home when Joshua was 15 days old. He came home with no feeding tube or oxygen. We were finally together - our family of five.

Our family will be forever indebted to the NICU staff in Craigavon Area Hospital, the NICU staff in the Royal Maternity Hospital Belfast and the staff in the Royal Belfast Hospital for Sick Children. The professionalism and expertise of all the consultants, doctors, nurses and support staff was first class and undoubtedly made what was a turbulent time in our lives that little bit easier. A particular word of thanks to Joshua's surgeon who is a truly amazing woman.

Joshua has just turned 5 months old and so far he is doing very well. He loves his milk, his sleep and listening to stories being read to him by his big sisters. I sometimes look back and cannot believe we have made it out the other side. We pray he will continue to do well in the coming months and years.



Joshua is our fighter, our miracle, our precious baby boy.



DISCLAIMER:

Alice Cheetham's CDH story

Alice Emma Cheetham was diagnosed at my 36 week growth scan. I laid there laughing and joking with the sonographer, until she went really quiet, she then said she needed to go get someone to help her get a certain measurement. It was not strange at this point as Alice never cooperated in scans, so I wasn't concerned till this lady came in had a look over Alice and said she had to go get someone else to come look... I started to get a little worried. I asked if something was wrong and her reply 'would you like me to get your husband to come in' (he was sat outside with Billy), with this I started to cry, as I new something was up.

We sat there quietly crying while three people looked at our baby. No one could tell us what was wrong at first and wouldn't give us a proper answer. They booked us an appointment at Manchester St Mary's hospital to get scanned by a specialist 2 days later.. longest 2 days ever. This scan confirmed the diagnosis; our Baby had a right sided hernia which give her a lower survival rate, also her heart had been pushed by her bowel into her rib cage on her left hand side, but he said her heart was working fine and in good condition.



DISCLAIMER:



Alice Cheetham's CDH story (continued)

He then said the dreaded sentence 'if she survives the first 48 hours'; our hearts broke. The baby that was so actively kicking inside me, suddenly we didn't know her fate.

We got home and looked at her bed beside ours and broke down. We no longer knew if we would ever get our baby home.

We went back a few days later to see the specialist in the NICU. They showed us round and gave us alot of hope with where our baby would be born and who would be the Doctors looking after her. They also gave us hope that everything would be okay with the fact of how late it was all found, as they couldn't see her lungs on the scan as of how far along I was and how late it was found he saw this as a good thing, but no one would really know until she was here. They booked me in to be induced the week after.

The day came all went well. After a quick and painful labour she was born 2.42am. The room was silent she was the most beautiful thing I have ever seen, but she made no noise.. The Nicu staff was on stand by and quickly started their work on her.. They expected her to cry. Panic struck are faces no one would tell us what was happening crowds of staff was round our baby girl. After they applied all the breathing tubes we got a quick look before she was taken away.... we waitied...

A few hours later the midwife came to collect us to go see her, she was covered in tubes, one of the machines was shaking her whole body, she was sedated, but when we held her hands and she heard our voices she started to open her eyes and kick. This wasn't supposed to happen, they then sedated her more.

The doctor came in to speak to us, he told us it was a lot worse that was thought, and Alice hardly had any lung tissue on either side and because of this the oxygen was struggling to pump round her body and they was struggling to keep her blood pressure up. She was on the most help they could give her.

They promised they were doing all they could for her and would call Liverpool to see if they would send the ecmo machine (a machine which goes into main vein to help oxygen circle the body).

A few hours later they came for us again, she was still on maximum support and was struggling. Liverpool wouldn't send the ecmo as it would no longer help. We got sent away again. We decided to call our parents to let them know she was born and things weren't looking good. They came for us again a hour later. Alice's skin had changed and was going grey, then they said it 'there is nothing more we can do, even with the top support, she was going and hadn't long left, 'would you like to hold her' I begged and pleaded for a moment, but I realised I was wasting time.

They passed me my tiny baby girl, she was so beautiful, she was gone.

We sat there crying and cuddling, it felt like a really bad dream, I really wanted to wake up and feeling her kick once again... this can't be our life... how can she be gone.? The Doctor then came to check her heart beat at 9.10am which we already knew she was gone. I cried at him even checking and pronouncing her dead.

They gave us some time then brought in a memory box to put things in for her, including the hat she wore in the incubator. There is more stuff in there including a blanket. I can't face looking at it just yet.

They then asked if we wanted to take some pictures, I knew we should but in that moment pictures seemed a weird thing to do and why would I want to remember this. They then started asking if we wanted to move to the butterfly room and if we wanted to bath her. Which I replied I couldn't. This I now regret. I wish I took the chance to bath my baby and dress her, instead of waiting for her to be brought back to me. While they had her they did foot casts and hand prints and stuff to add to our memory box.

After calling our parents crying she's gone, both our Mums arrived just in time to meet our little girl; she was all clean and dressed and wrapped in a lovely knitted blanket, she just looked like she was asleep so peacefully, my heart broke again as its was just another reminder she wouldn't wake up. I rocked her and cuddled her. They later brought in a huge moses basket with a canopy, I cried once again as they explained what a cuddle cot was, it's a bed to put them in which preserves their body so that parents can spend more time with their baby after they have passed on. After a hour we said our goodbyes and waited for them to

DISCLAIMER:

Alice Cheetham's CDH story (continued)

take her. They told us she wasn't alone and there was a little boy in the cuddle room with her, in some way this made me feel comfort but in another way my heart broke for the other parents feeling the same way as us in a different room.

I really wish I spent more time with Alice, but in that moment I just didn't know what to do, if I didn't put her down I don't think I'd have ever let go of her.

I wish I had spent more time with her that day, the day after I needed to see her again, Luke agrees to come with me as it was what I wanted, but it was alot harder this time. Alice was cold and her skin started to change, i shouldn't of let Luke come with me as this was too hard for him, I sat there cuddling her, Luke supported me but couldn't face holding her again. We went home that day.

We sorted out the funeral directors and they collected her from St Mary's for us, I visited her on my own a few times at the funeral home, I sang to her, I told her all about the family and how much I miss her and love her, I stroked her beautifully long hair, the photographer came to take some pictures of her, this was very strange but was told I'd regret it if I didn't have them. Which I'm so glad I have now.

The funeral I can't thank the staff at the funeral home and the Vicar enough; they all did am amazing job. Watching the strengh in Luke as he carried the tiny coffin to the church and then to her resting place with my Nan, Lukes job was always bed time with our Son and as he said it was only right for him to be putting Alice to rest.

We set doves off and thanked everyone for coming to say goodbye, we only had close family come; parents, grandparents and siblings and our 2 best friends.

This feeling will never go away we have good and bad days and we are trying are best to look forward to our future as a family with Alice watching over us.

DISCLAIMER:



Jessica Chapman

In June, Jessica Chapman aged 5 took part in the marathon in a month challenge for CDH UK. Jessica was born with LCDH in 2013.

She walked over 26 miles (28 in total) throughout June, and was joined on each walk of 3-5 miles by her amazing family and friends.









Jessica raised over £900 in total for CDH UK.

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CDH Fundraising

'Farvie'

Teddy was born in May 2017, with a full head of hair, beautiful brown eyes, and right sided CDH. He battled through ECMO, his surgery, and a 250 mile transfer to Alder Hey Hospital, but after 17 days, his little body just couldn't battle on anymore, and he passed away in June 2017. Teddy's fighting spirit was mighty, and has stayed with our family ever since, helping us to climb mountains (literally and metaphorically!)

Teddy's Grandad (or "Farvie" as we call him) decided this year to take on another challenge in his honor, and joined the 'Jog4June', walking a marathon in Teddy's name. Impressively, he travelled this distance with a hip replacement, knee replacement, and a fuzed ankle, raising £150 for CDHUK in the process.

Teddy's life may have been short, but his impact has been huge, and my greatest wish is that through his story, we can continue to help other families, whose battles are yet to come.



Teddy's Mummy x





'Farvie' raised £150 for CDH UK.

DISCLAIMER:



LA1 Construcion

My son was born in Manchester in July, diagnosed with LCDH at 20 week scan.

He had his Surgery at 3 days old and left the hospital after 3 weeks on NICU. The nurses and doctors there were truly amazing and looked after him so well. He has gone from strength to strength and is doing really well. I'm a partner in a construction company based in Lancaster and we took a team of 9 to the tough mudder NW in Cheshire on September 8th. 10 miles of mud and obstacles. We did it in around 3 hours and raised £1305 for CDH UK we proudly have the certificate on our office wall.

We raised a further £1244 for our local hospice.

Ell Sansom LA1 Construction Ltd





CDH UK FREEPHONE 0800 731 6991 WWW.CDHUK.ORG.UK

CDH Fundraising

Jan Lord

Jan Lord, Owner of Guide Bridge MOT and Service Centre who's garage forms part of the Masterserve Network of Independent garages, nominated the charity which is very close to their family at the moment.

Jan, a founder trustee of The MasterserveFoundation helped to launch it a couple of years ago with the aim of helping to raise monies for Charities related to Health and Social Care, she submitted her nomination in the last quarter for CDH UK, the charity set up to support those pregnant mums and their families who are affected by Congenital Diaphragmatic Hernia's.

Guide Bridge MOT & Service Centre, have certainly gone the extra mile again when along with her team, Jan was delighted to receive the news that they had been successful with their nomination and was able to help such a remarkable charity. Jan commented "we are absolutely delighted to receive this cheque from Masterserve for £4,500 and she was able to travel to Birmingham to present the cheque personally at the annual charity ball.

She goes onto say "We choose this charity as it is one close to our hearts. A baby born with a CDH has a 50% survival rate which is devastating. We're seeing close hand what CDH can do to a family such as ours and a good support network is vital. The charity are working closely with medical professionals to try and establish why it happens and therefore it's so important to support the charity. The charity not only helps expectant mums and their families through their pregnancy they also help when baby is born by assisting with hospital costs and specialised equipment should they need it.

CDH UK would like to thank Masterserve and it's customers and a special thanks to Jan Lord and family.



Jan Lord raised £4500 for CDH UK.

DISCLAIMER:

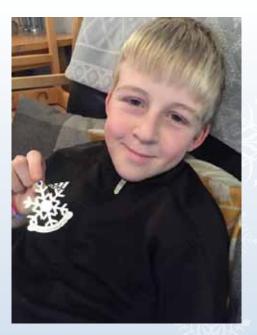


Sponsor a Snowflake Festive Appeal

This year's Snowflakes for our annual Snowflakes Appeal are hanging tree decorations and have gone down a real snowstorm again!

Thank you for supporting the appeal.

You can still purchase them until after Christmas and into the New Year on eBay.





DISCLAIMER:

Ernica update

Our work as a founding member of ERNICA continues and the last meeting was in Stockholm. We presented at the meeting about the importance of utilising patient representatives to their full potential.

The network has been working hard on moving forward with research and registries for all anomalies covered by the network and the 3-5 year plan for the network. CDH UK has accepted an invitation to become the patient representative on the ERNICA Scientific Committee, which we are very excited about.

The next meeting takes place in Italy in the Spring of 2019.



DISCLAIMER:

New committee members

This year saw us say goodbye to Committee member Matthew Smith who has served on the Committee for over two years. We would like to thank Matt for the time he has volunteered and wish him all the very best for the future.

We have also welcomed two new Committee members; Rachel Gallagher and Sue Bartlett.

Rachel is 27 and was born with CDH. She is not new to volunteering and is active with The Girl Guides. She is married with a daughter and lives in Scotland.

Sue has two Grandchildren one of whom is CDH survivor Jessica. She has a background in government services.

We hope that they both enjoy their time volunteering for CDH UK.





DISCLAIMER:

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27th

Rare Disease Day

28th

Dates for diaries 2019

January 26th Lancashire Family Get Together (see website or Facebook page for full details)

February 23rd 2019 **Scottish Families Get Together** (see website or Facebook page for full details)

February 28th 2019 **Rare Disease Day**

March 3rd 2019 World Birth Defects Day

June 28th 2019 **CDH** Awareness Day

October 9-15th 2019 **Babyloss Awareness Week UK**

Please see our website or social media accounts for further event dates.

DISCLAIMER:

The information in this newsletter is not to be substituted for medical advice. Every child is different and you cannot compare the progress of another child with CDH to the progress of your own child.

February

Scottish Families Get Together

2019

22nd

23rd

24th

25th

Colour in Nativity Scene

DISCLAIMER:

CDH Christmas Nativity Word Search



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Bethlehem Camels

Donkey Emmanuel

Frankincense Gifts

Jesus Holy Spirit Joseph Incense Manger Mary Shepherds Stable Myrrh Sheep Star

Wisemen

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



twitter









