Dear members, a warm welcome to you all, both old &new. It's been a busy winter here in
the broom cupboard, with lots of enquires & hospitals wanting to find out more about us. The
Cherubs Committee has also seen some changes with several of the original members
stepping down, to allow new blood to enter the picture. With this in mind I would like to express
our sincere thanks to the following committee members who have been with us since the start
& have all invested a lot of time in making Cherubs UK work for the families who need us most.
Jo Cowan, newsletter editor, Neil Cowan for technical support & Clare Kelly committee
member. Cherubs UK would like to wish them all well for the future. In the next newsletter I will
introduce you to our new committee members. Meanwhile you can still contact any of the
following committee at any time.

Brenda Lane       Chair
Michelle Flurry    Secretary
Donna Fahey        Treasurer
Natasha Lamb       Committee member and support for bereaved families
Rachel Wyatt       Committee member and on call Volunteer
Michelle Weber     Committee member and support for bereaved families
Please remember to inform Cherubs UK of any change of your name, address, or email address. If you could send the details (via email or post) to Brenda Lane at the address on p.23 it will help us to keep you informed of the work that we are doing. Thanks. If you would prefer not to receive newsletters and other mail from Cherubs UK, please contact us so that we can take your name off the mailing list.

The following letter is absolutely amazing. Thank you so much Marie for sharing Alan with us.

Hi Brenda

Finally got round to reading the newsletter and trying to deal with the emotions that come with it. I am a teacher at a local college and have to be “responsible” every day, and here I was falling to bits all over again, all these years later. However I think its time to get my story out if I can help, even one person cope better then I will be happy.

I’ll take you back to 1982, I was 22 years old and expecting my third child. We had married young and had just recently moved into our first house after living in a small flat, we had a four year old daughter and a two year old son and were delighted at the prospect of our third child. The pregnancy was unlike my other two pregnancies so we could not figure out whether I was having a boy or a girl. When I was about six months pregnant I had a routine blood test, a few days later I received a call from the hospital asking if I could come and donate some blood as I had leukocytes in my blood which could be used in research for premature babies. I was happy to oblige as my pregnancy was going well and I had no physical problems. The one strange thing was that I was completely obsessed with “what happens to babies who were stillborn?” The reason being was that a girl locally had had a stillborn baby and I was too scared and too naive to ask her any details.

It was a really weird time in my life, here I was pregnant in a lovely new house, a caring husband and two wonderful children and all I could think about was dead babies. A mother’s intuition or what. When I was about 36 weeks I thought I had a bleed only to discover that my “bleed” was what looked like muconium. I quickly showered and made an appointment for my gp that very day. I did not think there was any emergency, I did not know that this was probably the first sign of my baby being distressed. When I told my gp and my antenatal clinic they basically did not believe me, and said I must be mistaken as my baby seemed perfectly healthy and a decent size, my first two children were over 8 pounds. I began to doubt myself and carried on with my pregnancy. I still had this obsessive feeling of dread and was too frightened to discuss it with anyone except my husband, who almost begged me to stop being morbid.
As I got to term and not much was happening my doctor arranged for me to come in and be induced, I was exactly 41 weeks. On that morning we dropped my other two children at a friend's house early in order for me to go to the hospital, my friend told me later that on that morning there was no excitement at the thought of the imminent arrival of the new baby, just a 'we'll see what happens'. My friend thought this very strange but put it down to nerves at the prospect of the oncoming birth. We got to the hospital early and I was induced at around 9am, everything was going well and I was given an epidural. Epidurals at that time were not very common, and in my case did not seem to work. I was not numb and by the time the staff realised that the block was not successful it was too late to repeat. I remember there being lots of students in the delivery room with the midwife.

During labour I was suddenly aware that the students had been replaced by doctors. I later realised that this was when my baby became distressed and things changed very quickly. Alan was born just after noon; right away I knew something was wrong. I held him for a few seconds before he was put in a cot to the side of me. The doctors seemed to be standing over him doing all sorts of stuff. My husband trying to save me from worrying was standing between me and the cot, I eventually screamed at him to move just to see him being wheeled out of the room. I don't remember how many times but it was quite a few that different doctors kept coming back into the room to tell me 'your baby is not doing too well, do you understand? I stupidly said of course I did, but I didn't. Over and over again the doctors kept telling me that he wasn't doing well, my husband suggested he go and telephone our parents to inform them of the birth I flatly refused and said 'wait and see.' Time was going on and I did not know what was happening. I knew our baby who we decided to call Alan was not doing too well, but never in my wildest nightmare did I actually realise what this actually meant.

My husband Les went out to the father's room in order for me to be cleaned up, at this point the doctor came and found him and told him Alan had died, he was 1 ½ hours old. My husband was distraught and asked the doctor to come and tell me as he could not tell me face to face. As soon as that doctor walked into that room I knew the news was bad. She had tears running down her face, and she just said “I’m sorry your baby has just died” I felt as though I had been struck with a brick, the staff had been trying to prepare me for the worst but nothing prepared me for the shock.

I do remember stupidly asking what happens now? We were told to contact our undertaker; I mean what young family has an undertaker? We were asked if we would like to see him, anyone who has been in this situation will know that holding your dead baby in your arms is something that you will never forget. He was beautiful, perfectly formed and over 8 pounds in weight, so what was wrong and why had he died? I had no answers. I don’t actually think I held him for very long, and my husband didn’t hold him at all, a decision he has regretted ever since. We were asked about a post mortem which we agreed to, and suddenly I was back on an antenatal ward full of pregnant women.

It was a local holiday weekend and the post mortem would not be done for a few days. I was on the ward with the screens pulled around and I could hear whispers etc. I was numb. Very soon a very kindly older auxiliary nurse came to see me and said she had telephoned for a priest. I am catholic and he came and baptised Alan. I remember thinking “its a bit late for that” the same nurse brought me a single photograph of Alan which I now treasure. Very soon the priest came to see me and I was very bitter, I could not see past the fact that my baby was gone. Eventually the screens were pulled back and I felt as though I was on show, everyone was very nice, but with that sympathetic face.

The next day I became quite ill and ended up back in theatre as it seems in all the panic a piece of afterbirth had been left behind. A few days later I was told I could go home after I was
given the post mortem report that day. My husband came to the hospital where we met with the doctors; I was both eager and frightened to know what had happened. I was never given the chance to see Alan again. They told us that Alan had a diaphragmatic hernia which had stopped his lungs developing properly. I had never heard of this and there was virtually no information available. We went home and buried our son at a very private funeral, myself, my husband and my priest. That was the saddest day of my life. We decided to have it private as no one had got to meet him, and although he was very real to us, I did not want to share our precious time with him with anyone else. On the day of the funeral my husband carried that tiny white coffin to the graveside, I distinctly remember the gravedigger crying, and he was only a young boy probably a yts guy on work placement. My little girl who was then four would continually ask if she was extra good would she get a new baby as promised, she just did not understand. My son who was two was too young to know any different.

My problem was that I did not know what to do next, my family didn’t live near me, and we weren’t that close, my husband’s family were a lot older and were of the opinion that we should forget about everything. It was only at my 6 week postnatal check that I was given a detailed explanation on CDH and how it affects you. Life was a struggle and I would go over details in my mind over and over so as not to forget. I went on to have another child who was born very premature with a few problems but who turned out fine, but I would never forget Alan. In those days you did not talk about such things, anytime I tried to talk to someone the subject was very quickly changed. The fact that no one seemed to know what CDH was did not help. In all of the last 24 years I only ever met one person who knew what I was talking about and she was a student nurse friend many years ago.

Over the years I have looked up medical books and got snatches of information on CDH. I have never discussed Alan with anyone other than my husband for 24 years. My children know all about Alan and only recently asked exactly what happened. I felt that at their age now 28, 26, and 23, I really had to find out as much as I could about this condition, and what were the odds of grandchildren possibly being born with it. With the help of modern technology I searched the internet and found Cherubs. I could hardly believe it.

For years I thought that maybe I had the name of the condition wrong as no one knew what I was talking about, and all of a sudden I was not alone. I would like to see information given to any parents of children born with this condition. I was told 24 years ago that only a very small percentage of children born with CDH survive. Modern medical advances have made these odds a lot better. I would also urge hospitals to inform parents of Cherubs and make that support network well known. It has taken me 24 years to put my story to paper, and it still feels like it happened yesterday, I will never forget Alan but you do learn to live with your experience and your grief. My children are now all grown up and are responsible young adults with good careers, I am very proud of them. But I do sometimes wonder how different my life may have been if I had Alan, your quote in the newsletter is very surreal.

“An angel in the book of life wrote down my baby’s birth and whispered as she closed the book too beautiful for earth.”

What makes me tell my story now? It’s maybe just time.

Thanks for the opportunity and I will keep in touch
From the past we move on to a more recent account of having a baby with CDH. Thank you Claire for allowing us to include your story.

**Kacey’s Story- by her mum Claire**

When I found out I was pregnant again for the second time it was a surprise, because I hadn’t planned on another baby, but once I got used to the idea it was great.

Things were going fine, I only had morning sickness for 9 weeks everything was plain sailing after that and before I knew it I was at my 20 week scan.

During the Scan I was told the baby had a Diaphragmatic Hernia we had no idea what this meant as we had never heard of this and all the nurse said was that the Diaphragm had not sealed and the stomach contents had gone up into the chest cavity and we needed to be referred to the John Radcliff Hospital in Oxford.

I just broke down in tears praying we would not lose our baby.

We were told we had an appointment at the John Radcliff the following day and that for the duration of my pregnancy I would be in the care of John Radcliff Hospital.

We went to Oxford the following day and met the staff on the Fetal Medicine Unit and they explained to us what a C.D.H was, and to tell you the truth it scared us a little.

We met the Paediatric Consultant that would deliver Kacey, we had found out it was a girl during the scans this was the name we had chosen.

It was explained more in detail about the C.D.H and there was a 50/50 chance of survival rate, and also there could be Chromosome problem resulting in Downs or Edwards Syndrome, I was asked if I would take an Amnio test.

I decided against the Amnio test after all if there was a Chromosome problem nothing could be done about it and the risk of loosing Kacey was too great after carrying and feeling her kick for 5 months.

I was having scans every 2 weeks because I had increased Amniotic fluid and also blood tests done as I had Anti Kel Antibodies from a previous blood transfusion.

At one scan they thought Kacey had a heart defect as they found a V.S.D in the heart chamber but as the weeks went by it disappeared.

I was getting bigger each week due to the increased Amniotic fluid and at one point they considered a fluid drain.

The decision to have a C-section at 38 weeks was taken as our first child was delivered this way and it would be less stressful to Kacey.

It was all arranged for the 3rd September 06 so I went into Hospital on the evening of the 2nd; sitting there I thought this time tomorrow Kacey would be with us. On the morning of the 3rd I was starved all morning only to be told that the delivery could not go ahead as there was no room in the SCBU I was very disappointed and it was the same for the 4th and 5th but in the early hours of the 6th Sept 06 Kacey had decided enough I’m coming out.

I started to contract every 5 minutes so they contacted the PICU who would accept Kacey as they were not that busy, so I was prepared for theatre that afternoon.
After the spinal block and epidural had taken effect I was wheeled into theatre and Kacey came into this world at 15:45 on the 6th Sept 06 she even cried which surprised me as they said she would not be allowed to cry. But it made me feel good to hear her cry.

The doctors got to work on her straight away and she was sedated I felt awful seeing her lying there so still. After about 15 minutes and noticing I was crying they wheeled her incubator around to my side and let me have 5 minutes so I could see and touch her then she was taken away to the PICU.

The following day we went to meet Kacey properly she looked so tiny lying in the cot with all the tubes and drips around her and I felt so helpless but I knew she was in good hands.

I visited her every day and talked to her for 4 days, on the 4th day the surgeons decided she was strong enough for the operation to repair her Diaphragm and so she was taken to theatre.

I could not bring myself to say goodbye as she went because I was so scared she wouldn’t come back.

But 2 hours later I got a phone call to say the operation went well and Kacey was back in PICU doing fine, it was such a relief I could not wait to go and see her.

As the days went by Kacey seemed to get stronger, she was taken off the paralysis drug and she started to respond to my voice, even squeeze my hand and her eyes began to open

The nurses said she was great as she just tolerated everything they did to her without any fuss.

It was amazing the progress she was making even the surgeon commented on how good her progress was.

Kacey was off everything within 2 weeks the only thing she was on was the c-pap to help her oxygen levels.

She was being fed by an NG tube but when she was 5 weeks old we tried her on the bottle and she seemed to take to that ok.

So by this time it was felt Kacey was strong enough to be transferred to my local hospital which was a great relief as we had to do a 60 mile trip each day to Oxford and it was beginning to take its toll on us.

Kacey went on improving she was still on C-Pap but the time spent on it was decreasing each day.

So eventually she came of C-Pap altogether and was doing fine without it.

Kacey finally came home on the 8th November 2006 with the NG tube still in as she used to get tired using the bottle and she needed all her feed to gain the weight.

It was strange to start with as I was not used to her being beside me on a night, she was gaining weight slowly and this seemed to be the thing that most concerned the Health visitors and dieticians

I felt they did not appreciate Kaceys condition always saying she was under weight for her age but what could we do about it.

We had got to the stage where she was on 90mls of Enfamil milk and Duo cal every 4 hours and that was all she would tolerate, any more and she had bad Reflux.

She also suffers with very bad Eczema so bad we have tried a variety of skin creams to no avail and she has now been referred to a dermatologist
It was fantastic having Kacey home for Christmas and her sister Chantelle (5yrs) adored her and played with her the best she could and always trying to help me dress and feed her.

Our first setback came just after the New Year Kacey developed Bronchiolitus which was odd as she was getting the Palivizmab (RSV) jabs to protect her against it.

I was feeding Kacey one night using the NG tube but sensed something was not right as Kacey was screaming but her eyes where rolling and she drained of colour then went blue around the mouth.

By the time the Ambulance arrived Kacey had stopped breathing, I thought this is it I’m going to loose her but the Medics got her breathing again put her on oxygen and her colour slowly returned.

They kept her in hospital that night and most of the following day. It was confirmed by x-ray that she had an infection on her right lung (Bronchiolitus) and was given antibiotics through a line on admission and sent home with oral antibiotics, she had coughed up some milk and it had gone into her lungs.

Kacey is now 22 weeks old and having solids once a day and weighs 9lb 14oz.

We have had some fun with her pulling the NG tube out she does this a least 2 times a week.

She has been referred back to the John Radcliff Hospital for a tube to be inserted into her stomach.

All in all we have a long way to go before we sort her problems but she is a happy contented little girl

Who has a smile for everyone, catch her on a good day she will have a conversation with you but only she knows what she is saying!!

As I write the final line to this story poor Kacey is back in Hospital with suspected Bronchiolitus again. She also gave the nurses the run around as she pulled her ng tube out 3 times in 24hrs so they got see the problems we were getting at home with it.

Just another knock back on this long road for myself and Kacey

My thanks go out to Cherubs UK for all the support given I don’t think I would have got this far without the help and understanding given.

Claire. (Kaceys mum)

I would welcome your comments on the style and content of the newsletter, good or bad. I would also be delighted to receive any contributions for the next newsletter - stories of your Cherubs, inspirational poems or songs, ideas for fundraising, book or website reviews, medical information - really, anything that you think would be of interest to anyone touched by CDH. We would also be delighted to hear about the birth of any subsequent children, and we always like to hear how Cherubs are doing! Please email your comments and contributions to Brenda Lane at. 43 Vancouver Avenue, Kings Lynn Norfolk PE30 5RD. Thanks!
Letter from Zoe Garnett mum to surviving Cherub Robert

Congratulations for the 5th edition of the newsletter. It’s a regular reminder of how lucky we are and more important that we’re not alone.

I may be one of the silent members (actually I’m lousy at letter writing). But like every fortunate Cherubs parent I’m grateful that I have 3 fit and healthy children today.

My son is some ‘Cherub’! He is now nearly fifteen years old and like any teenager, hates to be told what to do. The horror of his birth and survival back in December 1991 seem a long while ago and only surface when he suffers the odd reflux or extra tiredness that CDH children have.

The biggest problem we have is convincing people that this apparently fit and healthy teenager is not quite what he seems! That his lack of attention in class is not because he had a late night and his lack of balance is because he has mild scoliosis and one leg longer than the other. Fortunately he’s long outgrown his reputation for being sick at children’s parties. People do seem to think that all hernias are easily repaired without any side effects!

That said, as he heads towards his GCSE’s he has not often had time off school, he now bakes a nice cake and he’s due his last appointment at the Sheffield children hospital. Now we are arguing whether he goes to his dates at the Adult Respiratory Clinic on his own and that discussion is still going on and on.... Teenagers!

PARENT MATCHING

We are hoping to start "parent matching" in the newsletter. Here is how it works: if you want to get in contact with other parents of CDH babies, write to us or email us (contact details on p. 22) and say, for example, "I am a bereaved mother from Cornwall who would like to get in touch with other people locally who have had a similar experience". We will then print your details in the next edition of the newsletter so that people can get in touch with you directly. You can send us whatever details you prefer – address, phone or email. We hope it will enable anyone affected by CDH to be directly in contact with others, if they so wish.

For Parents with Toddler Cherubs

Emma’s update

1. Here’s an update on my Cherub Emma, who was born with on 2nd August 2004 with a Left sided Diaphragmatic Hernia., and is now 2 and ½ years old.
2. In as far as anyone born with CDH can be lucky, Emma has been. Her CDH hasn’t left her with any long term problems. She had all the stays in hospital with chest infections and bronchiolitis that all CDH parents come to expect, but 2007 brought Emma a big milestone with one full year without hospital. Apart form the ups and downs with feeding and lack of weight gain that all of us are familiar with and a bit of speech and language therapy. I can’t
quite believe that who I see now when I look at Emma is that tiny baby on life support just a while ago.

3. I feel that the random situation we find ourselves catapulted into with CDH teaches us a lot about ourselves, our families and friends, that perhaps people without experience of CDH might never get the chance to realise. The fact that it is so random inspires feelings of anger, confusion, even guilt. Want to scream “why me?” I know even know I still feel some. The answer to the question “Why?” is so elusive, and that lack of an answer leads to so much frustration for CDH families.

4. I’m sure I can’t be the only CDH mum who feels a bit guilty when I catch myself taking Emma for granted in the daily routine of family life, especially when I tell her off for being naughty, because it’s pure chance that she managed to stay with us, and she so very nearly wasn’t here at all, every so often, when were out at playgroup or on a walk I can feel my eyes fill with tears for no particular reason or else I smile inanely again for no other reason that Emma’s here. I think other mum’s especially the ones who don’t know Emma’s a Cherub, must think I’m slightly unhinged. I think that comes to all CDH parents – it sends us all slightly mad at some point or another.

5. When Emma has tantrums, and shows the spirit she was born with, as she often does, I can ignore the stares of people watching, because only she and I know that determination got her where she is today, and I’m proud of her for that. When I tell her that she is my little Cherub, she’ll tell me “I’m not, I Emma”.

6. Emma starts nursery five mornings a week in September. I hope she’ll grab the opportunity and love every minute. How am I going to let her go? I know I can, because being a CDH parent is all about finding an inner strength that you never even realised existed, and that’s one of the many gifts that CDH children give to their parents.

CAN YOU SEND A COPY TO YOUR LOCAL HOSPITAL?

If you think you could send a copy of our newsletters either to the hospital where you had your baby, or where he/she had surgery, then please let us know so that we can send you extra copies. This will be a good way to help us to help more parents in this situation, by letting them know of the work that Cherubs UK is doing. Many thanks.

The following article has been reproduced by kind permission of the Daily Mail & Erin’s parents Alison & Simon Cottington

The 20-month-old girl kept alive by Viagra

With her sparkling green eyes and mischievous smile, the oxygen and feeding tube Erin Cottington wears constantly is the only outward clue of her uphill struggle for survival.

But the key to the 20-month-old’s battle to beat the health problems she has suffered since she was born is rather unusual - regular doses of the sex drug Viagra.
The toddler was first given the treatment when she was just a few days old to help her overcome life-threatening circulatory problems, caused by her underdeveloped heart and lungs.

Now she has one of the small blue pills each day to help keep her blood pressure down and stay healthy.

Although this may surprise those who know it as a cure for impotence, Viagra was originally developed to improve blood flow to the heart in angina sufferers.

Last night Erin’s mother, Alison, 33, said: “We can laugh about it now and find it amusing that Erin is being treated with Viagra, but it has helped save her life. “At the time she was so terribly poorly, the doctors thought we could lose her at any time, but she has fought it all. “The drug has been vital for helping swell her arteries and keep her blood pressure down. She has a bit more than one pill a day, crushed up in water, but the doctors think that as she grows the dosage will get smaller and she could eventually grow out of it. “We are just thankful to have her with us; her will to live has stunned everyone.” Doctors at St Mary's Hospital, Manchester, first realised Erin was not developing properly in the womb when married Mrs Stonington went for her 20 week scan. But it wasn’t until she was born, one week premature, weighing just 5lb 13oz, in June 2005, that they were able to assess exactly what was wrong. They diagnosed a diaphragmatic hernia - a rare condition which affects around 4,000 babies each year that is caused by a hole in the diaphragm.

In Erin’s case, she had virtually no diaphragm on the right-hand side of her body which meant that her intestines and bowels had pushed into her chest cavity as she was growing in the womb, crushing her right lung and heart and stopping them from developing properly.

Immediately after she was born doctors rushed Erin to intensive care and put her on a life-support machine. But they knew that without specialist treatment that she wouldn’t make it through the night, so they decided to fly Erin by air ambulance to Yorkhill Hospital, Glasgow.

There, medics placed Erin on a heart and lung bypass machine to pump oxygen into her blood and help her breathe. They also pumped artificial blood into her crushed right lung to help it increase its capacity.
Erin was given Viagra to open up her blood vessels and improve the blood flow around her body. She also had eight operations, including three to repair her diaphragm and open heart surgery to stem bleeding between her heart and lungs, before she was three months old.

“The doctors basically told us that if Erin stayed in Manchester she would not make it,” Mrs Cottington, a full-time mother, from Blackley, Manchester, said.

“It was awful, they prepared us for the worst because they didn’t think she would make the transfer in the helicopter, let alone cope with the treatment. But she kept battling and we were thrilled when they said she could come home.”

After more than 10 months in hospital, Erin was finally allowed out of hospital in April last year and is now on the road to recovery.

She is still fed through a tube and requires oxygen at night, but doctors are pleased with her progress and say she is developing like any other normal child.

Dr Carl Davies, a consultant paediatric surgeon at the Royal Hospital for Sick Children in Glasgow, who treats around six children a year with similar conditions, said: “Erin was very sick when she arrived with us - she was the most intensively-treated child in the world at that time.

“We have been using Viagra for a very small number of children for a few years and believe it can be very useful for a few patients. She will be tested to see its impact and will grow out of it. Most children stop taking it by the time they are two or three.”

Last week, doctors in Newcastle revealed they had also used Viagra to help a premature baby boy to breathe. Lewis Goodfellow, who was born 16 weeks premature, was given the drug to help open tiny blood vessels in his seriously underdeveloped lungs.

**Donation Thanks**

This is a very special page where we are able to say a huge thank you to all our supporters for helping to keep Cherubs Uk, running so that we can continue to help as many families as possible who have found & need our support so badly. So we would officially like to thank the following people

The Mayor and Mayoress of Wirral, Councillor Peter and Mrs Mary Johnson, gave a donation of £100 from their charity fund after they came to our Wirral Walk fundraising stall last May. They were very interested in Cherubs and CDH and were lovely people.

Rachel Wedgbury £318. Raised from a raffle at Barr’s Hill School and Community College. Coventry in Remembrance of their son Charlie

Michelle & Paul Richardson & their company MannVend for the sponsored bed push

Julie Dangerfield £5.00 monthly donation

Donna Fahey £ 5.00 monthly donation
Major Award given to Cherubs UK from Royal Bank of Scotland & the kind readers of the Daily Mail in the ‘Make It Happen Awards’ The Award was for £10,000.

With this large sum in mind we would like for you ‘our’ members to have a say in how we use the money. All ideas & suggestions will be fully discussed at the next Cherubs committee meeting.

So, we would like as many off you as possible to send in ideas & suggestion as soon as possible. Some of the areas you might like to think about are, Information, Support Services both for surviving & non surviving members, The Running of Cherubs UK or any other ideas you may have? Please send all your suggestions to Brenda Lane at 43 Vancouver Avenue, King’s Lynn, Norfolk, PE30 5RD or e-mail to brakha88@hotmail.com

Fundraising co coordinator

We have a new fundraising co- coordinator here at Cherubs UK so if you are planning an event, or would like some ideas ,please get in touch with Nina Griffiths on 017982 529183 or write to nina_griffiths@hotmail.com She will be happy to help you out with any forms / posters etc .you might need for your event.

Thank You Nina for volunteering for this post & good luck.

GIFT AID FORM

Included in this envelope you will find a form called “gift aid declaration” which we would really like you to fill in and return to us (at the address on page 22) if you are a taxpayer and you have ever donated money to Cherubs UK in the past, or intend to in the future. It will enable us to claim back 28p tax on every £1 donation made to us. You will see that this really does add up to a lot of money for Cherubs that would otherwise go to the taxman! Many thanks.
Cherubs UK Get Together
Saturday July 7th at Milton Keynes
Please let Rachel know if you would like to come
& if you require any special diets or extra help.

We are a friendly bunch & both survivors & non survivors get a chance to meet & chat with other families. Any siblings are also well entertained throughout the day. There is no charge for attending this event & if you need accommodation we can usually arrange this too. Cherubs UK will also hold it’s AGM on this day to which everyone is welcome.

____________________________________________________________

Please return the following form if you would like to come by June 1st so that we can organize the catering. Rachel Wyatt 40 Tudor Gardens, Milton Keynes, MK11 1HX

Adults ..........  Children............

Special diet Yes/No .......... If no please specify................

..............................................................................................

Any extra help you think you may need......................................

Accommodation Yes /No.................for how many?
The following poems have been written by Debbie Blakely to remember her son Joel. Thank you Debbie for sharing your feelings with us all. I do hope they will inspire some more members to put pen to paper so that hopefully there is a poem in every newsletter.

**WE SAW YOU**

*We saw you on the scan*
*And we watched you grow and grow*
*And how we hoped and prayed*
*And how we love you so*

*We saw you move your toes*
*We saw you move your fingers*
*We saw your hair grow longer*
*How those memories linger*

*We prayed that you’d get better*
*We prayed you’d be okay*
*We prayed we’d bring you home*
*We prayed that you’d stay*

*There were tears when we saw you*
*Fighting for your life*
*There were tears when we held you*
*Fighting with all your might*

*Our hearts broke as we held you*
*Our hearts broke when you died*
*Our hearts broke at that moment*
*And remain broken inside*

*All my love my beautiful baby*

*Love mummyxxxxxx*
I CAN AND I CAN’T

I can tell you the wonderful feeling you have when you are told at
the scan that everything looks good.

I can’t explain to you the hopeless feeling you have when you are
told your beautiful baby has a life threatening defect

I can tell you how motivated you are to do everything you can to
ensure your baby is born well

I can’t explain to you the feeling of hopelessness you have when you
know whatever you do it isn’t going to help your unborn child

I can tell you how wonderful it is to be pregnant, feel your baby
moving and to be able to talk about your baby

I can’t explain to you how hard it is to be pregnant and know that
the minute your baby is born he will be fighting for his life

I can tell you how exciting it is to be able to shop and nest ready
for your newborn

I can’t explain to you how hard it is being pregnant and being to
afraid to buy anything in case your baby dies

I can tell you how exciting it is to pack your baby’s bag for when he
arrives

I can’t explain to you how difficult it is to wash and pack an
outfit, knowing you may be dressing your baby in it after he has died

I can tell you how wonderful the sound of your newborns cry is

I can’t explain to you how devastating it is when your baby is born
but is unable to cry or breathe on his own

I can tell you how wonderful it is to see your newborn look at you

I can’t explain how heartbreaking it is to only once see your little
newborn look at you

I can tell you how wonderful it is to hold your newborn immediately
after birth and snuggle them close to you
I can’t explain to you how broken you feel when the first cuddle you have with your newborn is as he is dying in your arms.

I can tell you how wonderful it is to tell your newborn you love them. I can’t tell you how heartbreaking it is to tell them you love them but understand if they can’t fight anymore.

I can tell you how wonderful that first baby bath is.

I can’t explain to you how hard it is when the first bath is also the last bath and your baby has already left you.

I can tell you how wonderful it is every time you hold your new baby.

I can’t explain to you what it feels like to hold an angel in your arms.

I can tell you how proud you feel when you walk out of the hospital with your new baby.

I can’t explain to you what it feels like to leave your baby there and walk out with no more than the cases you arrived with.

I can tell you how proud you feel when you go to register your baby’s birth.

I can’t explain to you how it feels when you register his death at the same time.

I can tell you how wonderful it is to sit and plan your life with your child.

I can’t explain how it feels when that lifetime is through after just 17 hours 48 minutes.

I can tell you how wonderful it is when you receive all the new baby cards.

I can’t explain how it feels to get bereavement cards instead.

I can tell you how exciting it is to plan a christening.

I can’t explain to you how hard it is when days after giving birth you have to plan a funeral.

I can tell you how wonderful it is spending your days with your baby.
I can’t explain how it feels going to the cemetery to see your son
I can tell you how great it feels buying things for your child

I can’t explain how it feels walking past clothes imagining what they would look like dressed in them
I can tell you how wonderful it is seeing all your baby’s firsts
I can’t explain how it feels to only be able to imagine them
I can tell you how great it is telling people how many children you have

I can’t explain to you the terrible guilt you feel if you don’t include your angel
I can tell you how proud you feel writing all your children’s names on cards and things
I can’t explain to you how difficult it is to find a way to include your angel child without people raising their eyebrows
I can tell you how great it is to look at your children’s photos
I can’t explain to you how hard it is when you know the ones of your angel will never change

I can tell you about all the funny things my children have done
I can’t explain how it feels when the only memories I have of my baby are of him fighting for his life
I can tell you the fun you have arranging your child’s birthday celebrations
I can’t explain how hard it is to plan your baby’s birthday and angel days to
I can tell you how wonderful it is be able to talk about your child I can’t explain how much it hurts when people feel uncomfortable and change the subject

I can explain how much you miss your child when they are away for a day or two
I can’t explain the feeling you have when your child is never coming back
I can tell you how much joy you feel in looking after your child and keeping them safe

I can’t explain how it feels to only be able to hope and pray God is looking after your baby for you

I can tell you how overwhelming I love all my children including Joel

I can’t explain to you how overwhelming this hole in my heart is

I wrote this poem just before Joel’s 9 month anniversaries. There are so many things I miss and have missed doing with my little boy. At times it seems a lifetime ago he left us. I know how incredibly lucky I am to have my other children; I just wish that Joel was with us all here too.

Thank you for taking time to read this
Debbie

In the last issue there was a question and answer section called “How do I deal with the death of my baby?” Michelle Weber sent this reply, but it was too late for it to be included, so I said that I would include it next time.

“There is no easy way to answer this everyone deals with their grief differently. There is no right or wrong way to deal with the death of a child everyone is so different. Some people might want to talk about their baby others might just want deal with it privately which ever way you choose to cope is up to each individual. Hope this has helped it is such a hard question to answer.”

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Do you need financial help for your seriously ill /disabled child?  
The Family fund can help. This charity can help by giving grants to help you care for your child, Examples of help they may be able to offer are clothing & bedding ,driving lessons, holidays and outings ,transport expenses, moving home or hospital visiting costs ,appliances such as washing machines, tumble dryers and fridge freezers.

For grant enquires please call 0845 130 45 42
Or Apply online www.familyfund.org.uk
Breath of Life

The baby girl was going to die. Her only hope was a surgeon in London and an operation that had never worked before.

BY AILEEN SALLERTY

t was a long, anxious walk to the hospital, with the mother, father, and baby in the back seat. The baby was born with a congenital heart defect, and the only chance for survival was a heart transplant. But the baby was too small to undergo the surgery, and the family was绝望.

As they drove home, the mother cried and the father held her tightly. "We can't lose her," he said. "She is our everything." The baby was sleeping, but even in her sleep, she was in pain.

The family was referred to a specialist in London, who was willing to perform the surgery. The parents were overjoyed but also worried. They knew the risks, and they were not sure if the baby would survive.

The surgery was a success, and the baby began to recover. The family was overjoyed, but they knew that the baby would need a lifetime of medication and monitoring.

The family was grateful for the specialist's help, and they were determined to give the baby the best chance possible. They were relieved to see the baby grow stronger, and they were happy to see the baby begin to walk and talk.

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surgery, but I am not going to lose you as a patient. You will not leave me with a seriously disabled daughter." Maria and Peter opted for the operation. The choice was terrifying, but it was clear that if anyone could succeed it was Nicolaides and his team. The surgeon had pioneered the use of ultrasound to detect seven-year-old, the face of the infant's heart, and was one of the first to introduce fetal blood transfusion in the womb.

But for all his skill, the operation on Maria's baby was daunting. Nicolaides carried out nine previous operations with two close colleagues, and all patients in the hospital's obstetrics and gynecology ward, professor (an Irishman from London) and Edward Gracias from Mumbai, India. They had operated on as late as possible—31 weeks, when the babies would have the best chance of surviving any premature labour.

Both operations went well, which made it all the more dismaying that the lungs failed to grow. Neither of the babies had suffered side-effects from the operation. What had gone wrong? The specialists could only speculate. They knew that by 20 weeks a baby's lungs may be programmed not to grow until birth.

For the next operation—on Maria—they decided to operate earlier—at 26 weeks. It will make a difficult operation still more demanding. He has to be bold," says Nicolaides.

Then, as I am a parent of two young children, he is aware of the immense trust Maria and Peter are placing in him. "When I see a fetus, I see the child that will be my own child. It is a great responsibility."

Twenty weeks into her pregnancy, Maria's belly is burgeoning. Worry and concern are written all over her face as she is allowed in to the operating theatre. Some 3D specialists from around the globe have gathered to witness this pioneering procedure. Nicolaides greets Maria's aunt, and four surgeons—Professor Deppe and Gracias, two people are highly trained surgeons, the best in the world. I am very optimistic," he says quietly.

As-Maria's belly is lifted, Nicolaides picks up the ultrasound machine and everything else fades from his mind. He focuses on the monitor above the table. It will be his eyes, guiding him as he uses minute instruments, some barely wider than a human hair.

Nicolaides makes a firm decision on Maria's abdomen. "Breech position." He inserts a sharp metal instrument, a probe called a utero-artery probe. It is done to the baby'sanks, or umbilical cord, that the surgeon will pass to open. It is a small instrument, some barely wider than a human hair.

Nicolaides makes a firm decision to Maria's abdomen. "Breech position." He inserts a sharp metal instrument, a probe called a utero-artery probe. It is done to the baby's ankles, or umbilical cord, that the surgeon will pass through the baby's chest to open the umbilical cord again, and then to open the umbilical cord to start the initial operation.

Carefully avoiding the placenta, Nicolaides passes the probe through Maria's uterus and enters the amniotic cavity. He uses gentle, firm pressure to open the umbilical cord, and his hands are gently placed on the baby's head.

"The baby is in the best possible position," says Nicolaides. "The baby is in the best possible position," he says. If they prove too large, there is a real risk of rupturing the placenta and entering the space, which may be very risky.

"Then, all is well again. In the distinctive daylight hours, the baby's eyes open and Maria's baby is seen to be breathing and moving."

Maria's baby is seen to be breathing and moving. "The baby is in the best possible position," he says.
Home Start

Home start is a national charity that helps families with young children who need support at home. Several of our members have used their services in the past so if you think you need some help give them a call on

0800 068 63 68
support@home-start.org.uk