

## from us to You

bereaved families share their journey through grief

Published by Little Hearts Matter

We thought we would highlight our book which was written by families sharing their experience

of loss. All of our members should hopefully have received a copy, if you don't have one but would like a copy do get in touch with the office and we can send one out.

Here is an extract from the book, highlighting a grandfather's experience.

## Resources

Below is a sample of some websites and organisations which you may find helpful.

### SANDS

Supporting anyone affected by the death of a baby.  
www.uk-sands.org  
Tel: 020 7436 5881

### The Compassionate Friends

Supporting bereaved parents and their families  
www.tcf.org.uk  
Tel: 0845 123 2304  
helpline@tcf.org.uk

### Counselling Directory

Lists qualified/registered counsellors and psychotherapists in your area.  
www.counselling-directory.org.uk



Your thoughts on a get together...

We are considering holding a future bereavement event and would love to hear what you would like from this event/opportunity to meet up. We want to ensure we are offering the type of event people want and would attend.

Below are some ideas of the kind of things we'd like your thoughts on.

### Practicalities

How far would you travel to attend such an event?

What type of venue would you prefer, if a hotel, would you want accommodation?

If the event was held at a weekend, is Saturday or Sunday preferable?

Would holding it in the school holidays be easier?

### The Event

Formal/structured, introductions, speakers, remembrance, etc?

Totally informal, chance to mix and chat?

Sit down meal or buffet?

Separate area for children with activities?

Please email the LHM office at info@lhm.org.uk or call 0121 455 8982.

We look forward to receiving your feedback.

The Bereavement Team

## a grandfather's reflections

"The suffering and death of a grandchild brings grief to a whole family. A grandparent must also witness the pain and distress of one's own child and their partner in bereavement. These are the deepest waters we pass through, and everyone must find his own way. How can a family help those at the centre of such events? My experience leads me to offer my own ideas in the hope they may help others.

### 1. The route through grief is a personal journey

Writing three years after Benjamin died, I know that bereavement is a journey, a process, a growth from anguish and loss towards some adjustment that can be lived with. It has to be gone THROUGH because there is no way around.

There is no fixed or 'normal timetable; each must travel at the speed which can be managed and is right for them. We need time to do our grieving and must find ways to do it, desolating though it is."

### 2. Grief needs to be met with acceptance and sharing

"What a family must do to help is to accept grief and mourning for what they are; to bear with the cries of anguish and the silence of suffering. Mourners NEED to talk and therefore need patient, sympathetic and loving hearers. Not many words are needed (in the early stages at least). Certainly there are no easy answers."

### 3. The death and funeral

"My grandson died after 7 weeks and 6 days of life. We were brought the news in the middle of the night. Shock and grief were stunning. I can't bear to write of what my daughter and son-in-law went through"

"Express your grief; share it as a family; let the story be told and retold; and listen with love and care."

"Grief consumes energies so don't wear yourself out in doing too much, leave the things that can be left. When invited, share the issues that arise."

Extracts from a grandfather's reflections

## Lights of Love

This year our switching on ceremony will be held on Sunday 5th December, in the West Midlands.

Everyone is invited.

To dedicate a light visit [www.justgiving.com/lhmlightsoflove2010](http://www.justgiving.com/lhmlightsoflove2010) or contact the office.

# from us to you

## Newsletter no 2



## Welcome

Welcome to the summer edition of the 'from us to you' newsletter. We hope that you find the contents both interesting and useful.

As many families have asked us for information about a future

pregnancy we thought that it might be useful to include this information in this edition.

We also have a very personal story from one of our members.

Please remember that the Little Hearts Matter team is here if we can ever offer any help to you and your family.

Suzie



**This year our fourth On Your Marks for Little Hearts will be taking part on Sunday 3rd October at the stunning Shugborough Hall in Stafford. We would love for you to join us there: you can either come and take part or come and cheer on all the runners and walkers.**

**The Groves family have taken part in the last three. Here is what they had to say about the event...**

"For the last three years we have taken part, as a family, in the Shugborough run. As Peter and I are strangers to any kind of structured exercise routine the 5K option was chosen, which also meant our daughters, Charlotte, Bethany and Samantha, could join in.

When we registered it seemed like months away and the suggested 'training regime' never quite happened. So we were one week away to our first event, with none or very little preparation and we were beginning to panic!

When we got to Shugborough the place was packed with families all looking very athletic, but we needn't have worried as when we looked closely there were plenty of people like us, just there to support the event and LHM.

After booking in we watched the

## On Your Marks for Little Hearts Sunday 3rd October 2010



children's event and this put things into perspective as there were children with heart conditions taking part, giving it their all.

After a warm up the run or rather walk started. The five of us began as a group but split up as our daughters ran off without us! It was a fantastic feeling when we eventually crossed the finishing line being cheered on by the spectators and previous runners and made all the huffing and puffing worthwhile!

Obviously there is a more serious side to this event and the reasons behind us taking part were primarily to raise funds for LHM but also the event gave us the opportunity of publically 'recognising' Stephanie, our daughter who died of HLHS, 16

years ago. We proudly wore her picture on the back of our t-shirts, like many other families who had lost their sons and daughters.

This one event is where families can be together whether they have lost children or if they have children who have a serious heart condition. We were all able to be there together to support and encourage each other.

We would really recommend anybody taking part in the event, either running, walking or just supporting, all equally as important as the main focus is on raising much needed funds for LHM, who without this support would be unable to offer the fantastic services that it does.

So come along and give it a go in October.

# Our Story

Donna & Dean Jones

**M**y story begins on the 24th September 2008 with a positive pregnancy test stick. Dean and I got married in May 2008 and begun trying for our first baby together straight away. The one month we decided not to try anymore as I was going to be starting a new job, BAM!, I get pregnant!!! I hadn't felt right for about a week; I just thought it was my period taking a long time to show with my usual premenstrual symptoms. For anyone who tries to have a baby, I had all the classics but never put two and two together; sore breasts, bloated, nausea, back ache... until a friend said to me could you be pregnant. I brushed it away and then it played on my mind so at lunchtime I went and bought a test. Fully expecting it to be negative, I was utterly gobsmacked but it said positive. I phoned Dean and said sorry for not doing the test with you but I never thought it would be a positive one.

The problem being my previous period wasn't exactly something you could write home about so we were given an early scan and our due date was pencilled in for 3rd June 2009.

On 15th January 2009, we excitedly went along for our 20 week scan. All we were concerned about was seeing the baby again and possibly finding out the sex. We never paid any heed to the sonographer when she said she couldn't see all four chambers in the heart and to come back the next day to see a consultant who would be able to scan me better.

Our life changed forever. they sat us down and said there was a problem with our baby's heart. They said that the left ventricle was smaller than it should be and they believed it was due to a Coarctation in the Aorta (COA). They said there was also the problem of a genetic disorder called DiGeorge's Syndrome or 22q deletion. They assured us that the Coarctation would be a minor operation, possibly a couple of days or weeks after birth and then we will go home and have our happy ever after.

Like most heart parents, I am sure we went home and did all the research under the sun and went armed with questions for our follow-up appointment, the following week.

The consultants were able to answer everything and again we were given reassurance. We were scheduled for a re-scan at 28 weeks on 11th March 2009.

Whilst we went with the knowledge at the back of our heads that we were going for a check-up on baby's heart, we also went with excitement at seeing our baby again. I wish this was good news but they said the left ventricle was smaller again since they last saw us and they were pretty sure it was now Aortic Stenosis (AS) with a possible COA. Again, we were reassured that it was a simple procedure, with balloon catheterisation. Again, it would be a couple of days in hospital, a week at most. We accepted this and moved on to the next milestone - 36 week scan on 6th May 2009.

During the next 8 weeks, I grow bigger by the second it feels like and go on maternity leave. By the time the 6th May comes around, I'm beginning to get fed up with being pregnant and want to have this baby out. I also go to the doctor at around 30 weeks as I was beginning to feel depressed I guess and anxious about the baby. Apparently, it was all normal because of the news we had been given and it didn't last that long.

There are dates that heart parents will never forget and from this point on it is all about dates and they are all tied to significant events. 6th May - we are told that baby's heart had changed significantly since the 28 week scan and that the doctors were concerned. So much so they sent us away to talk about inducing me. Me being me, fed up of being huge, not being able to bend down, to sleep comfortably etc I almost begged them to induce me...how I wish I hadn't. 7th May - got a phone call at 11a.m. from the fetal medicine unit to say they were inducing me on Monday 11th May 2009 at 9a.m. I was all excited; it was an omen, our 9 year anniversary!!

On the night before induction, I had a shower and whilst in the shower I

noticed I had a show... was I about to go it on my own? No, it wasn't meant to be.

We arrive at the fetal medicine unit at 9a.m. and after a quick scan, I am taken down to the Induction Suite. After an examination, I am already found to be 1cm - a good start for me! The pessary goes in and off we go on some walking to encourage baby to do something. And nothing happens. We return for some lunch and then decide to go over to the main hospital to have a look around the shops. I will never look at WH Smiths in the same light again... the first contractions begin and they don't stop.

At roughly 5p.m. they examine me and find I am a good 2-3cm and the midwife breaks my waters and takes me round to delivery. The contractions come thick and fast but after another examination at 8p.m. I am found to have only gone up to 3-4cm even though the contractions are appearing regular. After discussion with the doctors and midwife, it is decided I need to go on the Syntocin drip and I take the opportunity of being bed ridden to take the epidural too. Fast forward to 4a.m. and they finally examine me and I am almost 9cm!!! At 5a.m. I am fully dilated and left for an hour to see if baby will descend a bit further before pushing. After an hour of pushing, baby really doesn't want to come out despite my best efforts so we have forceps and at 8.14a.m., Charlie Eoin James Jones was born on 12th May 2009.

He came out blue and it took what felt like a lifetime to get him to respond. The doctors work on him and get him stable and bring him round to me, long enough for me to stroke his head and tell him I love him. He is then whisked away to the Neo-natal Unit.

## The booking scan

The booking scan, usually carried out by about 12 weeks of pregnancy, will hopefully be a positive affirmation that so far all is well and that the first hurdle of early miscarriage is past. Seeing the baby on the screen can bring a mixture of emotions as hopes and aspirations for this new baby combine with memories of scans in the previous pregnancy.

Further routine screening tests will also be offered to look for the risk of Down's syndrome and throughout pregnancy and the general size and growth of the baby will be assessed.

All parents of a child with a congenital heart condition should be given the opportunity to have a specialist fetal cardiology scan if they want one. This can be arranged as part of the booking process.

## How early in pregnancy can heart abnormalities be detected?

Unfortunately congenital heart conditions can only be detected by detailed ultrasound scan and traditionally scanning in pregnancy for the detection of heart abnormalities has been around 20 weeks of pregnancy when the heart is the size of a walnut.

As scanning technology and expertise of those carrying out the scans has improved, it is now possible in some fetal medicine centres to offer an initial scan at around 14 weeks.

Clearly for parents who have had a previously affected child, any reassurance which can be given earlier in pregnancy is beneficial. Parents would need to talk to their obstetrician to find out whether early cardiac scans are available in their area.

## What can be detected at this early scan?

The heart at 14 weeks is about the size of a pea and therefore it is not possible to visualise all the structures in the heart in sufficient detail to reassure parents that the heart is completely normal but it is possible to detect major abnormalities. The team will also look for other indications that the baby may have a problem for example the nuchal translucency - fluid filled space at the back of the baby's neck (see below).

If all of the tests are normal it is likely that the heart will be normal although a further scan will be arranged around 20 weeks for added reassurance.

## Why is a measurement of the nuchal translucency carried out?

It is known that there is an increased risk of the baby having a heart abnormality if the measurement of the nuchal translucency is larger than it should be for the number of weeks of pregnancy.

An increased nuchal translucency measurement is also a marker of increased risk of chromosome abnormalities such as Down's syndrome. If this was found to be the case, the clinician would discuss with parents whether they would like further tests to check whether the baby's genetic make-up is normal.

## What happens if an abnormality is found?

In the rare case that the fetal medical team detect or suspect that there is a problem with the structure or function of the heart they will organise for further scanning and other tests to be conducted.

Throughout the process expectant parents will be involved in discussions about the baby and any treatment path that is suggested for the baby and mother's care.

## What other tests are offered in pregnancy?

If there are indications that there may be an abnormality in the heart, other organs, growth or development of the baby further diagnostic test will be offered to obtain additional information about the baby's genetic make up.

**Chorionic Villus Sampling** takes a sample from the developing placenta and is carried out at around 11 weeks. The procedure carries a risk of miscarriage of about 1 in 75 and the first part of the result (the PCR test) looking at the three more common chromosome differences which includes Down's syndrome initial results are usually available in 3 - 4 days. The full results are usually available within three weeks.

**Amniocentesis** takes a sample of amniotic fluid from around the baby and is carried out at around 15 - 16 weeks. The risk of miscarriage is about 1 in 100 - 150 and the first part of the result (the PCR test) looking at the three more common chromosome differences which includes Down's syndrome, is usually available in 3 - 4 days. The full results take 2 - 3 weeks.

It is very important that parents are given adequate opportunities to ask

questions and voice their concerns with their doctors or midwives so that they ultimately feel comfortable with the decisions they make.

Whichever antenatal tests parents choose, waiting for the results will be an anxious time. Many parents choose to wait until they have had the reassurance of a normal result before telling other people about the pregnancy and this can be quite a strain, particularly if they have opted for a later test.

It is important to remember that most future pregnancies will have no complications and most importantly that the new baby will be born without any problems.

## The rest of the pregnancy

Most parents who have had previous problematic pregnancies, talk about the heightened sense of anxiety which remains throughout the pregnancy and how they worry more about other things going wrong, such as the baby not growing, not moving or being stillborn. This is a completely normal response to what has happened in the past and it is often helpful to talk to others who have had similar experiences as they will understand this mixture of fear and hope.

Midwives and doctors need to be aware of the increased anxieties that these parents will feel and allow time for them to voice their concerns.

## The birth

Most parents with no previous problems view the birth with some sense of trepidation. For parents who have memories of their previous birth and what they had to face following it, the birth will be a further time of extreme anxiety and dread that something might go wrong even at this late stage. It is not until the baby is finally in their arms, having been checked over and pronounced healthy, that parents will gradually begin to relax and look towards the future. To embark on a future pregnancy is a courageous undertaking, but for most couples it is well worth the emotional rollercoaster ride it entails.

*This article has been compiled from previous articles from Ruth Kirchmeier, Midwife in Fetal Medicine, Birmingham Women's Hospital and Sherrida Rollings, Paediatric Sister and Counsellor for Fetal Cardiology, Evelina Children's Hospital.*



# Future Pregnancies

## An emotional rollercoaster

If you have had a child affected by a complex heart problem, the thought of future pregnancies will inevitably be a scary prospect. Making the decision whether to try again is a complex one, coloured by the painful memories of what happened in the previous pregnancy or at birth when the diagnosis of a cardiac defect was made. For those parents who chose to end the pregnancy or whose baby died after birth or whilst undergoing treatment, there can be a conflict between treasuring the memories of the baby who died and the hopes of having a healthy child.

Although we know from research and experience that if you have had a child with a congenital heart condition, there is a small increased risk in future pregnancies, by far the most likely outcome is that you will have a child with a normal heart.

Your own individual recurrence risk will be given to you by your medical team, but the range could be anything from 2 - 3% to 9 - 10%. The factors influencing this include the exact nature of the condition your previous child had and your individual family background. However it may help to bear in mind that even if the recurrence risk is 10%, it means that you have a 90% chance of your baby's

heart being normal next time, and even if there is a problem, it would not necessarily be the same, or as severe, as your previous child.

Whilst statistics such as these are given to reassure you and help you make plans for the future, we know that when you have had a child with a congenital heart condition, it is hard to believe that it will not happen again.

### Preconception Care

Most parents will want to know if there is anything they can do to reduce the risk of recurrence. Whilst as yet, the causes of single ventricle heart disease are not known there are a few simple things that parents can do to keep themselves healthy and therefore give their baby the best chance.

- Eat a good balanced diet including foods rich in Folic Acid e.g. fruits, green leafy vegetables, lentils, chickpeas, some cereals and bread.
- Cut down on the intake of caffeine to reduce the risk of miscarriage.
- Reduce and if possible stop smoking prior to conception. Smoking can affect the fertility of both men and women and may mean it takes longer to conceive.
- Reduce and if possible stop

drinking alcohol prior to conception. Alcohol too can affect both men's and women's fertility.

- Take 400 micrograms of Folic Acid once a day ideally for three months prior to conception and for the first twelve weeks of the pregnancy. This is thought to reduce the risks of neural tube defects such as spina bifida.
- Exercise regularly to maintain a reasonable level of fitness.

### Facing the emotional impact of a further pregnancy

No one can take away the anxiety which the thought of a future pregnancy brings. Sometimes it might be helpful for parents to see their obstetrician or GP prior to embarking on a pregnancy, to talk through some of the issues surrounding how a subsequent pregnancy would be managed and what support could be given. For some parents, making a decision to try again can be helped by talking to other parents who have had an affected child and who have had a further successful pregnancy. Little Hearts Matter can put parents in touch with one another and these contacts can be valuable sources of support both prior and during a pregnancy.

At 2p.m. a cardiologist comes to see me and Dean. They need to operate on Charlie... NOW, and they need our permission. He tells us that Charlie is now over in the main hospital on the PICU but he needs urgent surgery to help save him. I cry as I hadn't seen him apart from those precious seconds after birth and hadn't even held him. Never mind the fact that my family were en route to me from London to see me and him. But needs must and Dean signed the consent form as I was still too weak to do so. We agree to catheterisation for Bilateral Pulmonary Artery Banding and Atrial Septostomy (tiny rubber bands placed on the two main tubes coming out of the heart to restrict the blood flow and a hole made between the two upper chambers of the heart); if needs must he will go for open heart surgery to complete the procedure.

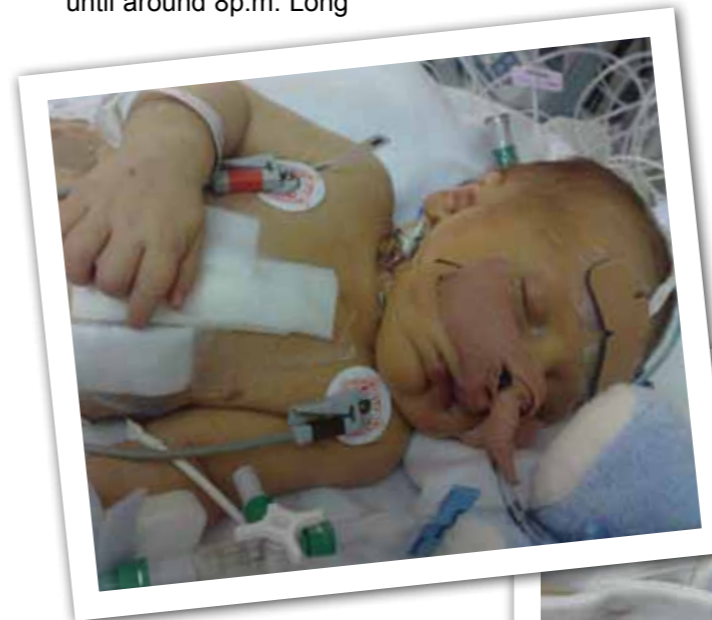
However you want to look at it, Charlie didn't end up going down until around 8p.m. Long

many others. He had a feeding tube in but wouldn't be fed for a while. I spent most of the day at his side, only returning to the maternity hospital for lunch, medication and dinner. Before leaving Charlie's bedside that night, I will never forget this for the rest of my life. Dean and I were sat on the right side of Charlie and one of the PICU consultants was sat on the left side on a stool, just staring at the monitor... he turned to us and said "it's not looking good, I am not sure if he will make the night". At 36 hours old, we were told that our precious baby might not survive.

Well, he proved him wrong. In the 3 1/2 weeks that ensued our stay in PICU, the doctors slowly learnt that Charlie liked doing things his own way. He dictated when he was happy for medicines to be weaned, how much milk he would absorb, he would give the impression he was going downhill and we were prepared for his Norwood (and at one point we were skipping the Norwood and going to the Glenn) as an emergency procedure but eventually we were only on oral medicines (except for Prostin) and he was absorbing milk. But there were also

weeks old, I got to hold him for the first time. We also were told there was nothing genetically wrong with him, no DiGeorge's. We had decided before he was born to have his cord blood tested and they came back clear.

I can't remember exactly when we found out the extent of his heart problem but I remember distinctly how. We were sat there one Saturday, doing a bedside vigil. Being a weekend, the unit was quieter and everyone was more relaxed. The nurses were discussing Charlie between themselves and they mentioned that he had 'Hypoplastic Left Heart Syndrome (HLHS). The nurses then became acutely aware that no-one had told us the extent of his problems. Meanwhile, I had text my best friend and asked her to do research for me and bring it in when she came to visit. Only when she arrived, she pulled Dean to one side as she was worried about what she found out. She told him that from what she found out was some children may not live until they are five years old and handed him the printouts she had. When he told me, of course I was upset but I vowed that if that's all we had then it would be the best five years of my life. I guess I also said it with naivety as I thought my little boy would fight and I would have



enough for his daddy and family to see him. Me, well I had to wait until the epidural had worn off and as I lost a lot of blood I had to fulfil certain criteria before I could even be wheelchair over.

At 4a.m. in the morning, we got the call that in the end he had to have open heart surgery but he was back on PICU and so far stable.

At 7a.m. my wonderful midwife gets permission to push me across to the main hospital so I could meet my son properly. In bed 6 of the PICU, I never saw all the tubes or wires or the ventilator, all I saw was my beautiful boy lying there. When I compose myself, the nurses explain the different medicines he is on. Prostaglandin to keep the duct open, Adrenaline, Morphine, Sedative, and

a lot of highs too; the first time he opened his eyes, squeezed our fingers, having his chest closed, being taken off the ventilator (he looked so pleased with himself) and the biggest high was when he was exactly two

him to eternity. I guess those words will come back to haunt me. On the Monday, one of the PICU consultants, took us to a side room and sat us down and talked us through HLHS, surgery and the future.

We made it up to the children's cardiac ward on Thursday 4th June 2009, a huge milestone for us. We went to grow and get stronger; a week later they came to tell me that they are going to do the Norwood on Monday 15th June 2009. We told no-one. Due to previous disappointments, we didn't want it to be cancelled again. The weekend before was so quiet on the ward, there was only three patients (including Charlie) and they sent the other two home on weekend leave. They moved us into one of the side rooms and let both of us stay the night at his bedside.

The night before the Norwood, we were so nervous, it was a hot summer. And it was hot in the room that night. When they took Charlie's temperature at 5a.m. it was a bit high and they thought he might be running a temperature but after stripping him down it came down, he was obviously just hot.

So the time came when we were wheeled down to theatre. It was the worst journey of my life. I had to hand over my baby boy and had no idea whether he would be coming back to me. Charlie had cried the whole time prior to leaving the ward, he was hungry, but as soon as we left, it was as if he knew and stopped crying and just stared at me. Whether it was just him saying it will be okay mummy, I will never know. Whilst sat in the pre-op area, we see one of the PICU

consultants and he says to us he will be in there with Charlie and that gives us some peace.

A long eight hours later, the surgeon came to see us. It was a success. We can go and see him on PICU in half an hour. I never felt so relieved in all my life. The phone calls followed to family and friends to tell them that a) he had surgery and b) he was still with us.

I remember walking into the PICU, an all too familiar environment and not hearing what the doctors were telling me regarding the surgery and just spying my baby boy lying there in bed space 2. I just wanted to hold him tight and kiss him all over and thank god he came back to me. This time there was no hanging about and five days later we were back on the cardiac ward. Ten days later (15 days post op) we are finally discharged with the NG tube in place.

We spend the next 13 weeks at home. On the 5th day of being home, Charlie is laid on the sofa with his daddy whilst I am cooking dinner and all I hear is 'Charlie, what have you done?' I come rushing in and he has pulled his NG tube out. We laugh about it and phone the ward, as he has been doing so well with his bottle feeds we are told we can keep it out until he begins to get fussy with feeds. Luckily, that day never comes. Yes, we do have problems with feeds, but more so the fact that he had infantri

milk which was thicker than normal formula milk as it was high calorie and therefore we had problems with teats. He still puts on weight every week and his community paediatric nurse is pleased with him every week. We stop needing to go to cardiac clinic every week and are told he needs a cardiac catheter in August, just to check his heart function better than they can on an Echo.

We gear ourselves up for a three day stay in hospital and go to the park before going into hospital. Charlie is duly starved the morning before and as I eventually get my hungry boy off to sleep, they come with bad news. The anaesthetist that is scheduled for Charlie's operation is not a consultant and they are not happy to proceed without one so the operation is cancelled and we go home.

Fast forward another month and we go in again for the cardiac catheter. This time it takes place and they inform us that his heart is enlarged and increase his dosage of Frusemide to try and shrink it back down. They tell us to come to clinic in ten days time for a follow-up and they will tell us then about Stage 2. We duly go along to clinic and apart from getting annoyed during the Echo we are given a clean bill of health and told that the surgeons have yet to discuss further surgery for Charlie.

On Thursday 1st October 2009, Charlie woke up as normal in a great mood. I had cuddles with him and gave him his bottle, breakfast and medication then went in to wake Dean up, as it was his day off. We all had fun cuddling and playing in our bed and when we got up Charlie was playing whilst we had breakfast. Dean took him for his bath and he started to grizzle but it was coming up to another feed and nap time so we thought nothing of it. Dean got him in and out as quickly as possible but he still didn't settle out of the bath, like he normally did. We thought he was just being clingy and wanted his mummy but I was going for a shower and he had to learn to be settled by his daddy. When I came out of the shower he was still grizzling and wasn't taking his bottle from Dean, I went to him and told him not to be silly and to calm down. Then every heart parents nightmare happened.

He started struggling to breathe and became raspy, he also went this funny grey colour. I wasn't happy and said to Dean who should we phone - in ten seconds I made my mind up and phoned 999 and as I was on the phone to the operator, Dean screamed at me that he had gone floppy. He had been walking around with Charlie, trying to get him to focus on something else. I screamed at the operator. It was then she told me we needed to do CPR, I took over from Dean so he could put the phone on loudspeaker and began giving my baby boy CPR. I knew as I was doing it, it was too late, he was already gone but that still didn't stop me trying to get him to come back.

It felt like an eternity until the paramedic turned up. But he did and I distinctly remember asking him if he was breathing and he said to me "not right now my love". He told Dean to go and wait for the ambulance and show them up and told me I needed to get dressed as we were going as soon as the ambulance arrived. I was still in my dressing gown following my shower; all I did was put my pyjamas back on. In the ambulance the wholdeway there, both mine and Dean's eyes were on the heart monitor and every time they stopped to see if his heart was beating, there was just a flat line.

We got to A&E and they tried so hard to get him back. I sat there to one side and remember wanting to scream at them to stop so I could just



hold my baby but also wanting them to bring him back. I turned to one of the PICU consultants who was sat with us and said he's gone isn't he and she said yes it looks like it. They told us that they managed to get his heart beating briefly but his body had already gone into failure. I asked them to stop and put him in my arms to finally go to sleep. The time was 10.50a.m.

Due to the nature of Charlie's death we had to have a post mortem. I had to know why he died. Was it my fault? Did I do something wrong? The answer, no. He died of heart failure due to HLHS. His little heart was 3 1/2 times the size it should have been.

Six weeks after his death, we found out we were pregnant again. By now, we already knew our chances of another HLHS baby was 2 - 4%. Surely, we couldn't have another child with HLHS? How wrong could we be? At 17 weeks and 5 days old, Kian Jones was born sleeping on Friday 19th February 2010. His post mortem showed, he not only had HLHS but he had a degree of atrial isomerism, bi-lobed lungs and partial malrotation of the intestine.

Our chances of having another child with HLHS now lie at 10%. We are told it is only a small chance but our response is 2 - 4% was smaller but we still ended up in that category. So where do we stand now? We are undergoing genetic counselling and will be having tests on our hearts to see if there is anything there. We are fortunate to be under the head of genetic testing and we are also being referred to a doctor who is



doing specific research into causes of HLHS.

I cannot and will not let my babies' lives not amount to anything, for as long as I live I will campaign to get more awareness into HLHS and hopefully one day, find a cure or get a reason for its occurrence. I don't like it being referred to as 'random'. It was not a random act that I was blessed with two gorgeous little boys who I adore, love and idolise; it was not random that at my darkest hour I was blessed with a tiny light at the end of the tunnel. Both boys were given to me for a reason and I will find out the reason why my heart had to be broken.

In November 2009 Dean myself and four friends founded the Charlie Jones Foundation, for more information visit [www.charliejonesfoundation.co.uk](http://www.charliejonesfoundation.co.uk)

