

Safe and Sustainable Update

Thank you to the many families who were able to complete and return the LHM Safe and Sustainable questionnaire. We are so grateful to have had your input.

The LHM team are currently formulating their comments to go to the consultation team by the 1st July 2011.

To ensure that all of our members have a full update on our response we have created a further Safe and Sustainable newsletter which is available on our website www.lhm.org.uk or if you would like a printed copy email us at info@lhm.org.uk or give us a ring on **0121 455 8982**.

There is still time to take part in the national survey by completing the Ipsos MORI form we sent out in the last newsletter or by going on line to www.ipsos-mori.com/safeandsustainable.

If you have any questions please just give us a ring.

Forthcoming Events

Lights of Love

For the third year running we will be lighting our very own 'Lights of Love' Christmas tree. This year's event will be on the 11th December 2011.

The aim of 'Lights of Love' is to fill our tree with lights every Christmas. Your lights can represent anything you wish such as remembrance, love, celebration, anniversaries, achievements and happiness. This event is now an annual one, reaching all our families across the UK.

Information about dedicating a light will be in future newsletters. However, this year we are suggesting that before the actual event that we have an informal 'tea and mince pies' time for members to get together and have a chat. Before we action these plans we need to know if you would, like this opportunity to meet other members in similar circumstances. If you would please email info@lhm.org.uk or call us on 0121 455 8982.

Last year's event was as successful as ever with everybody enjoying singing carols with members of Amington Brass Band with a glass of mulled wine before the lights were switched on. It was a lovely occasion to remember those who are not with us anymore and those things which are special to us.

On Your Marks for Little Hearts

Join us this year for 'On Your Marks for Little Hearts'. It's a fantastic event enjoyed by all our families, giving everyone the opportunity to meet up, have fun and of course raise funds to keep our charity going. It's great to meet other families who are there in remembrance of their children and the support you get from everybody is just amazing. The event has grown over the years and we all look forward to the occasion, even if you're not the fittest! Come in fancy dress and walk the course if you want, whichever way you prefer 'just do it!' Bring friends and family, it will be a great day to remember.

Little Hearts Matter

11 Greenfield Crescent, Edgbaston, Birmingham, B15 3AU
Telephone: 0121 455 8982; Email: info@lhm.org.uk
www.lhm.org.uk



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

from us to you
Newsletter no 1 2011



Welcome

Welcome to the first edition of the 'from us to you' newsletter for 2011.

If you would like to share your story or have a book, website or other

resource that you would like other members to know about please do get in touch by emailing us on info@lhm.org.uk.

Little Hearts Matter

Half a heart...not half a life

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

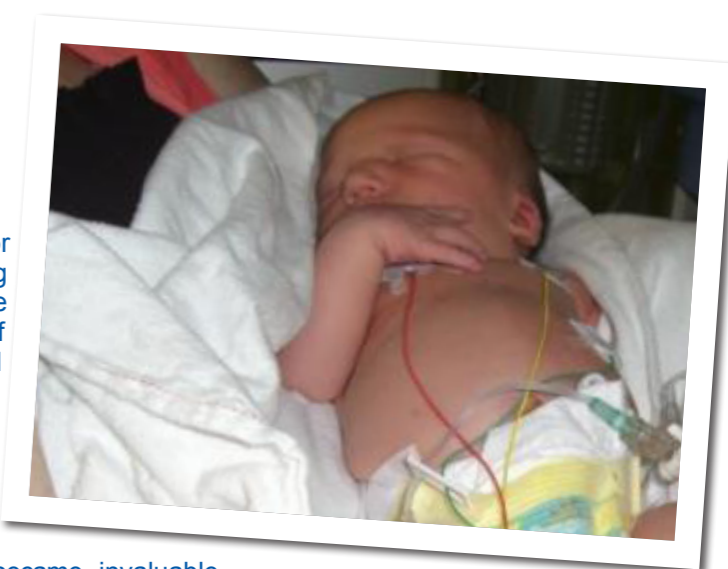
Graham's fundraising in memory of Rocky Beau

Rocky Beau was born on Wednesday 22nd July 2009. He had the appearance of a perfect baby and going with him to be assessed when he was first born I can recall looking at him thinking there must be a mistake, there were no external symptoms of HLHS and the thought of him having it did not seem feasible. However, the reality was he was born with a life threatening condition and subsequently I was only able to hold him on one more occasion. HLHS demands almost immediate surgery and an operation was scheduled. The emotional burden of a newborn child requiring surgery was further compounded by the news that my father had died not long before. This meant on the day of Rocky's operation I could not be with him as my time had to also be spent supporting other members of my family. I left though safe in the knowledge that his mother would be caring for Rocky and hoped and prayed he would be OK. Following my father's funeral I quickly went back to the hospital where Rocky was and sat patiently by his side. Sadly though my prayers were not answered, after an agonising 24 hours, he passed away at 11 minutes past ten on the 25th July.

Seeking solace and a platform on which to gain support, I contacted the charity Little Hearts Matter. In the months prior to Rocky's birth I had been made aware of the charity as a

safe haven for parents struggling to deal with the emotional stress of having a child suffer from HLHS. It offered me the opportunity to meet people who were in a similar situation as myself, something which became invaluable over the following months. One particular person was Donna Cornock, she had suffered the same fate with her son Jack in 1999. After conversing via the LHM message boards, we have become good friends and offer each other mutual support as we continue to adapt to the emotional stresses we have encountered. After finally meeting Donna face to face, it became clear that I had a responsibility to give something back to LHM. I signed up for a charity bike ride. It involves the rather daunting task of cycling from London to Paris arriving on the 5th June 2011, which is coincidentally, both mine and Jack's birthday.

This was the beginning of my relentless fundraising. Since that day family, friends, colleagues and outright strangers have been receiving constant pressure to donate money to the bike ride. There has been a multitude of events run and set up by myself to raise both money



and awareness, including most recently a charity football match. People happily turned up on a windy but mild Sunday morning and even though the majority of participants had not run since the last century a fantastic football match was had between 'Team Rocky' and 'Jack's All Stars'. This coupled with a wealth of other donations had taken my total up to £1900, well over halfway to my £3500 target.

Everyone at Little Hearts Matter at the time of Rocky's birth were an incredible support, this has continued to the present day. It is difficult to qualify just how much of an impact Donna and Little Hearts Matter have had on my life since. I had no qualms about signing up for the bike ride and even after I have completed the ride itself I will still be calling upon people to donate up until the 5th August, exactly two years since Rocky's funeral.

Graham Holder

Our Story

by Alison Turner

Our story starts in early 2002, when my husband and I arrived for our 12-week scan. I had had an early miscarriage with our first pregnancy, so we were looking forward to seeing that all was well with our baby this time round. So it was a terrible shock to be told that our baby had Meckel-Gruber syndrome - a rare, autosomal recessive condition that is uniformly fatal. We were told there and then that our child could not and would not survive after birth.

Ending the pregnancy never really crossed my mind. We weren't hoping for a miracle - we knew that our child was incompatible with life. It was more because we knew we were definitely going to lose him, that we wanted to meet him before we had to say goodbye.

The grief and pain of losing a baby was going to happen one way or another, there was no way around it - but we wanted some time to hold him and love him first.

Obviously I was monitored very carefully throughout my pregnancy, with ultrasound and MRI scans. We found out at around 16 weeks that the baby was a boy, and named him Will. It was around the 20-week mark, at one of the regular scans, that the sonographer spotted that Will's heart appeared to be missing the left ventricle. We were seen immediately by a fetal cardiologist, who diagnosed Hypoplastic Left Heart Syndrome (HLHS).

Although HLHS is not part of Meckel-Gruber syndrome, associated cardiac abnormalities have been noticed in the past, so it was generally assumed that the HLHS was probably linked to the Meckel-Gruber.

Because Will's prognosis was so dire anyway, the addition of HLHS didn't really make any difference - other than to increase the risk that he may not even make it to delivery. However, the early diagnosis meant that we had time to process the information we were given. We had to time to work our way through the shock, grief and lost hopes before Will was born. Knowing, as we did that our time with him was so very limited, we made the most of every minute we had with him before he was born.

I sang to him and told stories.

We visited places that we would have loved to have taken him to. I even sat through every match of the World Cup, so my husband could 'show' his son the football.

My pregnancy was an emotional rollercoaster - one minute I was revelling in feeling the first kicks and seeing my son's face on scans, and the next I was sitting on the floor, packing my hospital bag and howling. It was heartbreaking to pack one babygro, one vest, one pair of socks, one nappy and one little tiger toy - knowing that this was the sum total of my son's life.

However, the backup we received from the medical staff at our local hospital was second-to-none. Consultants, geneticists, pathologists, midwives... everybody. Once we had told them that we would be carrying Will to term, we were given nothing but help and support.

I delivered Will two weeks early by caesarean section on September 9, 2002. He was born alive and weighed 7lbs7oz.

That day, in the operating theatre, there was no panic, no shock, no shouting. Just an almost sacred hush and a quiet welcome for our son. The joy I felt as my little boy was placed, alive, into my arms is almost indescribable. We had an amazing

fifteen minutes with him - way more than we had ever expected. Time to hold him, sing to him and tell him how much we loved him. I cannot begin to imagine what a different experience it would have been if we had not known about Will's condition antenatally.

I'm not saying that carrying a terminally ill baby to term was an easy thing to do - it wasn't. But I would do it all over again.

Will's antenatal diagnosis gave me the chance to make that choice, and to have the privilege of cradling our son as he entered the world, and to hold him in my arms as, just fifteen minutes later, he quietly left.

We knew we wanted more children, and the following year, I became pregnant again.

Of course I was monitored extremely carefully because of my previous history, and we were terribly scared that our next child would have Meckel-Gruber syndrome.

By fourteen weeks, we were cautiously hopeful. There was no sign of the kidney or brain problems that would signal Meckel-Gruber syndrome.

At the sixteen week scan, the sonographer (the same lady who picked up Will's HLHS) was able to tell us that the baby - our second son, Charlie - did NOT have Meckel-Gruber syndrome.

But we barely had time to let out a whoop of delight before she told us: 'But there's a problem with the heart'.

I turned to her and asked 'Is it the same problem Will had?' and she replied: 'Yes, I think it might be.'

Needless to say, we were blown away by this news.

I remember ranting furiously - and slightly hysterically - as I lay on the couch. How could this be happening?

We had beaten the odds and had conceived a child who was free of the fatal symptoms of Meckel-Gruber, but now had a child who was facing an equally difficult, incurable and complex cardiac condition.

For the second time, the fetal cardiologist was called, and confirmed that this baby also had HLHS. It was a strange and surreal experience - on one hand, we were utterly devastated to hear that our baby had such a massive battle ahead, while on the other hand we were delighted to know that this child might survive. While I had been carrying Will, we had wished and wished that there was some hope - even one percent - but there wasn't.

This time we had around a 50 - 60% chance of our child making it to school age... and we grabbed it with both hands.

From a purely personal point of view, finding out about Charlie's heart before he was born meant that I had time to research the condition and to gain a proper understanding of what it meant in terms of surgery and future prognosis.

I was also able to find other people in the same situation. I stumbled across Little Hearts Matter - and the office team were able to provide a wealth of information for us to read so we could come to terms with Charlie's diagnosis. Equally, there was always someone on the end of the phone there, to answer the many questions I had.

I made contact with other parents through LHM's website, and mums sent me pictures of their reassuringly healthy and normal-looking children, and gave me tips and tricks to cope with the first stressful weeks in hospital.

Many of the parents I have met through Little Hearts Matter have become some of my dearest friends. There is nothing like having someone you can call on at any time, who you know will understand exactly what you are going through, and who will celebrate your triumphs and share your losses as if they were their own.

With both sons, we knew very early on about the medical conditions they would be faced with at birth.

The main downside of knowing the bad news earlier, rather than later, is that I have never experienced what you would call a joyful, stress-free pregnancy. I've had to break two lots of bad news to my parents - and watch them grieve for me AND their grandchildren.

I have had to deal with the 'Oh, is it your first? You must be so excited!' questions... do I just nod, smile sheepishly and agree, hoping that I never meet the person again, or do I give them all the gory details and end up apologising for ruining their day?

I've heard mums-to-be agonising over whether they might have a boy or

a girl, or whether they might have to have a c-section and have had to bite my tongue... wishing that was all we had to worry about.

I've never been able to wander around Toys R Us or Mothercare, happily choosing buggies, cots and babygros.

That's part of the fun of pregnancy which I've never had.

I've never, ever been able to think 'When the baby comes...' It's always been 'If the baby survives...'

I find it hard to imagine ever having a child WITHOUT major health issues. I've never known any different.

We've never been able to just think 'Oh, shall we have another baby?' We're constantly weighing the odds - knowing we have a one in four chance of Meckel-Gruber AND HLHS next time round. (Although Charlie says he'd rather like another sibling with a special heart like his!)

We would love another child, and hope that maybe we might be able to avoid Meckel-Gruber AND HLHS next time round. (Although Charlie says he'd rather like another sibling with a special heart like his!)

Charlie has now had all three of his surgeries. He had his Fontan in March 2010, again in Birmingham.

He left hospital three weeks and two days post-op, and his feet have barely touched the ground since.

He is top of his class at school, and at last, is able to keep up with his friends in the playground. His new Fontan circulation means he has more oxygen flying around his body, so he can walk, run and play without becoming blue and breathless.

He still has some limitations - he will never be the fastest runner (but he no longer always comes last!) and he'll never be able to join in with contact sports because of his pacemaker and because he is on warfarin - an aggressive blood thinner which is essential to keep his blood flowing smoothly through the gore-tex tube that was placed in his heart during his surgery. The warfarin levels in his blood have to be carefully monitored by blood tests which we do at home. We and his teachers have to keep a careful eye on him if he falls or is bumped in the playground, because his medication can cause excessive bleeding and bruising.

Some of his classmates are a little squeamish when they see his scars, but he is confident enough to be able to explain why they are there, and why they are so important... without those

precious scars, he wouldn't be here.

Charlie has been a blessing to us in so many ways - he and his brother have taught us so much. Living day-



to-day with a life-threatening condition - both before and after birth - really makes you get your priorities straight, and teaches you to appreciate every minute of every day. You can never be sure of tomorrow, so you make the most of today.

Every time Charlie achieves something new, he makes us so proud. He is a delightful, sunny-natured, chatty, smiley little boy who is loved by all who know him.

At the time of writing, Charlie is seven years old.

I was sixteen weeks pregnant when his HLHS was diagnosed, and we hardly dared hope that he would reach seven days... never mind seven years.

Because of the support we have been given throughout his life by medical staff, the team at Little Hearts Matter and of course, our friends and family, we were able to make informed choices about the best course of treatment for him, and to always be in the right place at the right time to give our little boy the best possible chance at life.

Our hearts sing as we watch him grow. We are so proud and privileged to be able to call him our son.