



# welcome

I would like to welcome you to the very first From Us to You newsletter written by bereaved families for bereaved families.

The Little Hearts Matter bereavement team Judith, Tracy and myself hope that this is the first of many but it will need your help to be successful as we hope to fill it with your stories and ideas for where families can find support as they, like yourselves, learn to live their life after the loss of their child.

We would welcome your newsletter ideas and your thoughts about this very first edition. Just give us a ring on 0121 455 8982 or email us on [info@lhm.org.uk](mailto:info@lhm.org.uk)

### Suzie

### Judith & Peter

"Peter and I became involved with LHM through our 'association' with Suzie, who was the Cardiac Liaison Sister at Birmingham Children's Hospital when we had Stephanie. We have worked with the bereavement team for a few years now and were involved with the production of 'from us to you'.

We mainly offer telephone support for families who



have lost their child but have met up with other bereaved families at the events Little Hearts Matter has held over the years. Peter is now a Trustee for LHM working with the rest of the team ensuring Little Hearts Matter goes from strength to strength."

### Tracy



"I am married to Andrew, I have a daughter Katie aged 15 and Marcus John who lost his brave fight from Hypoplastic Left Heart Syndrome (26/04/1999 — 30/04/1999).

I used to be a Trauma Nurse, but due to deteriorating asthma I have had to retire! I have been involved with the LHM bereavement team for many years now, mainly through the website and email. I have also attended bereavement events and spoke with other parents directly. Talking about my experience and Marcus with other bereaved parents I hope helps them in some way! But I also know that it has benefited me by helping me through my own grief and most importantly keeps Marcus' memory alive!"

## News

### Thank you Joanna Goldie

We would like to take this opportunity to thank Joanna Goldie who has been one of the volunteer bereavement team since the sad loss of her son Benjamin ten years ago. Jo took a lead in writing the bereavement book and supporting other bereaved LHM families.

Jo is stepping away from the team to support her other children as they start school. Thank you Jo - keep in touch.

### Bereavement Team

With the loss of Joanna, we would be glad of any extra support for our team.

If anyone feels able to offer their help please get in contact with us.

**0121 455 8982**

### Questionnaire

You will notice that included in this newsletter is a questionnaire. We would be extremely grateful if you could spend a few minutes to consider the questions.

The questionnaire has been designed to give you the opportunity to voice your opinion and to tell us exactly what you would like from the charity.

We would like to expand the bereavement services, therefore with this information in mind we can plan for future events, or for services we do not offer at present.

Please could the completed questionnaires be returned to the office by Monday 19th October.

## Lights Of Love

Our very own Little Hearts Matter 'Lights of Love' tree is now ready. We would love for you to join us on the **6th December** in Stafford (time to be confirmed) for a special switching on ceremony. If you would like to attend please call us on **0121 455 8982** or email [info@lhm.org.uk](mailto:info@lhm.org.uk)

If you would like to dedicate a light for a loved one please visit [www.justgiving.com/lhmlightsoflove](http://www.justgiving.com/lhmlightsoflove) or you can complete the form sent out with the last newsletter, or call or email us.

# personal stories

## Tracy & Andrew's Story

We lost our amazing little boy Marcus John ten years ago! The story started to unfold on Christmas Eve 1998! We attended the 20 week scan, I was not apprehensive at all, I had threatened to lose Marcus at 12 weeks, but that had all passed and I could feel him moving loads! The sonographer said she could not see the baby's heart very well and fetched someone else, they then both said that they wanted a doctor to scan me as baby was lying 'funny', we therefore had to go home and come back later that afternoon!

The doctor scanned for ages and then informed us that the baby had a terrible heart defect "incompatible with life" and also she thought the baby had Down's Syndrome! We had to wait until New Year's Eve to attend Birmingham Women's Hospital! Christmas has never been the same again.

Eventual diagnosis was Hypoplastic Left Heart Syndrome, not Down's Syndrome.

We were at first not offered surgery as Marcus had a lot of fluid around his heart and tummy; they said he was too poorly! We made the decision to continue with the pregnancy and have comfort care for him at the end. However in April things changed, his condition improved and we were offered surgery if he was ok on delivery.

We therefore had him at North Staffs Maternity Hospital, so that if

comfort care was still the option he was close to family! He was delivered by planned C-Section on Monday 26th April 1999 at 11.58. He was amazing, he looked perfect, he was transferred later that day to Birmingham Children's with dad; however they did not let me follow for two days!!! He had surgery on Friday 30th April; it lasted eight hours (the longest eight hours of our lives!!!).



However, one hour post-op Marcus lost his astounding brave battle and grew his angel wings at 21.00 hours! We spent the most wonderful next five hours with our special little man. Part of us went with Marcus that day; we will never be the same people again! We say we went to hell, I don't think we will ever get back to paradise, but with LHM support we have found our own tranquillity!

## Too Soon By Mary Yarnall

This was a life that had hardly begun  
No time to find your place in the sun  
No time to do all you could have done  
But we loved you enough for a lifetime

No time to enjoy the world and its wealth  
No time to take life down off the shelf  
No time to sing the song of yourself  
Though you had enough love for a lifetime

Those who live long endure sadness and tears  
But you'll never suffer the sorrowing years  
No betrayal, no anger, no hatred, no fears  
Just love, only love, in your lifetime

## Christmas Cards

We are now selling special Little Hearts Matter Christmas cards and we also have a new initiative this year - the alternative Christmas Card, a poster card which can be displayed in your place of work for example and each person pays a small donation to write a message

For more details on either of these please visit the website - [www.lhm.org.uk](http://www.lhm.org.uk) or call us on 0121 455 8982 or email [info@lhm.org.uk](mailto:info@lhm.org.uk)

## Judith & Peter 's Story

After a very healthy and uneventful pregnancy Stephanie Rebecca was born, nine days late, on the 31st March 1994. She was perfect in every way and everything we had ever hoped for.

Our families all travelled from around the country to meet her and we took many, many photos of those happy times. During my second night in hospital, the 2nd April, Stephanie began to show signs of being ill and after being checked at our own hospital we were

rushed down to Birmingham Children's Hospital. We were soon told that Stephanie had become extremely poorly and sadly there was nothing that they could do for her. Stephanie was christened and then died in our arms.

Fifteen years later and we have learnt how to cope but there are still times when the reality of what happened hits



us as if it were yesterday. Birthdays and Christmas can still be difficult but on the whole we manage to live and remember her with happiness.

We now have three more daughters. Charlotte who is 14 and Bethany and Samantha who are 12. They know all about their 'big' sister and always include her in discussions about their family.