



Young at Heart

Supporting families of children with heart conditions

Newsletter No 3: Oct 2006

NEW Information Line 0121 357 8200

Charity News & Update

I hope you all had a lovely summer and as we pack our parasols and BBQ's away and those summer evenings are just a distant memory, dare I say but Christmas is just around the corner and of course that means enclosed are our Young at Heart Christmas raffle tickets slightly later than usual, this was due to us having to re-apply for a licence and registration number to enable us to sell them, this has taken a little longer than we first anticipated.

Our Christmas raffle is one of our biggest fund raisers and without your continued support we would not be able to fund the children's Christmas party so please do not hesitate to contact Sue on our information line if you require anymore to sell, this would be very much appreciated.

Also enclosed is a Christmas Party invitation for you to complete and return to us by the 15th November, this will confirm your place and we will then forward your Christmas party ticket. This years Christmas party will held on the 2nd December 2006 at the Aston Villa Football Club in McGregors suite, 2.00pm till 5.00pm.

N.B. Strictly siblings only, we cannot accommodate other children at the party due to the cost involved.

Don't forget too collect your pennies too hand in, once again there will be a prize for the highest collector.

Since our last newsletter we have been actively involved in the problems surrounding operation cancellations at Birmingham Children's Hospital and currently have several meetings lined up in the near future. We would like to take this opportunity to thank all of you who sent out YAH's letter to their MP's, we have had several responses.

Young at Heart feels very strongly about this subject, we are working with the trust and cardiac team to address these issues. Earlier this summer I had the chance to meet and speak with Shelia Shribman, National Clinical Director for Children, at a meeting held at BCH, it was an opportunity to express our concerns regarding paediatric cardiac services within the hospital, progress is being made and we will keep you up to date with any information with receive.

Our AGM was held in July and I have to say that this would have been a great opportunity to have met with a few more of our members, we were disappointed with the lack of people who attended. I must remind you that Birmingham Children's Hospital is regarded as one of the leading centres of cardiac treatment and we work hard to ensure we have very close links with BCH and it is of most importance that BCH have a strong support group which is of course Young at Heart.

It is with great sadness we have to inform you that Sarah will be resigning from her role as Treasurer. She has worked really hard over the last 18 months and on behalf of the Trustees we would like to take this opportunity to thank Sarah and wish her all the best for the future. Sarah is still staying on the committee as a Trustee.

A new Treasurer will be appointed shortly.

I look forward to seeing you all at the Christmas party.

Vice Chair: Debra Bailey

COMPETITION FOR THE KIDS

Guess the Committee member as a child and win £10, simply match the correct picture from **then** and **now**

THEN



Match the correct pictures and send your answers to:

Young at Heart

42 Thetford Road,

Great Barr,

Birmingham. B42 2HY

Please return your entry by 20th

November 2006

The winner will be drawn at the Xmas party — Good Luck.

NOW



FUNDRAISING NEWS

ASDA BAG-PACKING DAY

We would like to thank everyone involved in helping with this fundraising event which took place on 16th September.

We managed to collect £631.06 in total.

MOBILE PHONES

We are still collecting any unwanted mobile phones, so please continue to collect them on behalf of Young at Heart. If you have any phones to be sent to us and require a recycling bag, please either contact the information line or e-mail: youngatheart sue@yahoo.co.uk

MOLLY'S DOLLY

For many of the children who have a congenital heart disorder they will need heart surgery. Molly's Dolly, a rag doll with a scar, is an easily identifiable replica of a scar that a child may have. They come in boy and girl dolls.



These dolls are available from the Children's Heart Federation and are free of charge where the order is endorsed by a health care professional (e.g. Cardiac Liaison Nurse). For more info visit :

www.childrens-heart-fed.co.uk

DONATION & FUNDRAISING - THANK YOU'S

COLLECTIONS

Londis - £27.37

CK News - £22.32

DONATIONS

J9 Window - £25

Doreen Lisk - £295.00

Pat Hughes - £670.00

Mike Ponsonby - £20.00

Joy Kortbeek - £25.00

FUNDRAISING

Phil Hatfield - £132.00

Village Hall - £337.50

Joy Kortbeck - £107.42

Deb Bailey - £170.00

Mr Hodson - £20.00

Julie Chapman - £940.00

Maria Gill - £234.00

Sally Scruton - £300.30

Thank you to everyone involved in raising funds on behalf of Young at Heart

OUR MACCA

What can I tell you about the bravest and most precious son in the world!!!

Macauley has not long turned 10 years old – a very big mile stone, considering I was told that he would not reach his 1st birthday. Macauley was born with Pulmonary Artesia and AVSD, he was baptised and taken from Coventry to Birmingham Children's Hospital. At only 26hours old Macauley had his first heart operation a BT shunt, a couple of weeks after this Macauley was still in intensive care and struggling, as you can imagine I was worried sick. Doctors did a Cardiac Catheter and I was told Macauley's shunt was too narrow and he would need a central shunt. I wondered how life could be so cruel, my new born baby going through so much pain, but something in side me told me Macauley was here for a reason. I cried as I signed the dreaded consent forms, just praying for the best. Macauley had a central shunt and after a few days was allowed on the ward. He had feeding problems; projectile vomiting, a barium meal showed a hiatus hernia. He had a thickener added to his feeds, luckily he was 8lb 8oz born, so once he started gaining a little weight he was allowed home. I was scared to take him home, I was worried about looking after him properly, making sure he had all his medicine and fed well. Macauley was also born with a left refluxing kidney and with no spleen- the list just seemed to get longer! When I looked at my little boy his big blue eyes told me things were going to be alright.

At 9 months old Macauley went back into hospital to have his second stage. It seemed even harder, he was our little Macca now, we knew him now and he was a big part of our family. How I wished I could swap places with him. Macauley was struggling and deep down I knew he needed this second stage. The operation was successful and Macauley seemed to be doing well (but the thing you learn with heart children is that things can change very quickly!). Macauley started to struggle once on the ward, he was getting very poorly – the strange thing was, his heart was doing okay. Lots' of specialists came to see him, x-rays were done and then they discovered Macauley's bowel had been missed during bypass and he had a hole in his bowel, the contents of his bowel had given him Septicaemia. Macauley was rushed back to theatre, I was told to expect the worst. On top of a major heart surgery, Macauley had suffered Septicaemia, bowel problems and the odds seemed stacked against him. Once out of theatre, he was left on the ventilator, with lots of antibiotics to give his body a rest. You just wouldn't believe he was out of I.T.U and on the ward in 3 days!!! What a 'hero' and that was his new name 'my little hero'. Whilst in hospital Macauley also had a acid test as he was still struggling with keeping food/bottles down and was diagnosed with reflux. Due to the bowel op Macauley had to go on a lactolose free diet for 6 weeks. We got home just in time for his first Easter and he wasn't even allowed to have a chocolate egg, as they contain lactolose.

Just after Macauley's 1st birthday we noticed he was scrunching his left hand, he'd stopped clapping, waving or using it. It was really strange. I took him to Walsgrave hospital where a CT scan showed he'd had a stroke; he was put back on aspirin and referred to a home physiotherapist. Macauley never crawled he shuffled on his bottom, using his strong arm to pull him around, he was fast and into everything! At 2 years old Macauley took his first step, I cried!

At 3 years old Macauley was doing okay, considering all his problems. Just when we thought there could be no more problems, Macauley just suddenly had a real bad fit, his eyes were rolling, he was blue and his body was jerking and shaking, I ran with him in my arms to my neighbour who phoned an ambulance. After some oxygen he calmed a little. At first the doctors at Walsgrave were going to give medicine for fits, as this had eased things. After he'd settled down the real problem was seen. The left side of his face had dropped, he was dribbling, he couldn't talk or walk, it was another stroke. I just remember thinking my poor, poor baby he has really had enough. Macauley spent a couple of weeks in hospital and once discharged had a lot of physio. It was like starting all over again, but 'my little hero' improved everyday.

Just two months after starting Reception, Macauley was struggling and the dreaded 3rd stage was looming. He was actually booked in for February to have the fontan, but by November he was 100% needing the operation once again . I couldn't think things could be harder but, we'd had him 4½ years he belonged with us, he didn't do all this fighting to give up now!

So Macauley had his fontan operation, it was hours, the waiting was awful. I remember writing in the chapel's special book and just praying. My prayers were answered Macauley's operation had gone well. The first two days were so up and down I literally broke down! Once on the ward he improved all the time. He had the horrible drains in, but he played up and down the ward with his fluid bottle in a little shopping trolley, if that had been an adult they would probably have been in bed moaning, not 'my little hero'. We got home just a few days before Christmas, guess what Macauley was on a fat free diet due to the fluid in his chest, no sweets, chocolate etc for Macauley. BUT IT WAS STILL THE BEST CHRISTMAS EVER!

Macauley is now 10 years old and he is absolutely wonderful. He's a proper lad, none of this 'my little hero' business. He likes to be called Macca. He is popular at school, everyone loves him. He can have his moments, but on the whole he has a lovely, kind nature. He's a bit shy to new people or crowded places, but at home there's no shutting him up. He's quite active, he scares his teacher in P.E., she said to me " you would never believe he has a heart condition", she also said "he never makes excuses, he'll have a try at everything". I am so proud of him, the last 6 years have been so good. Macauley has had good quality of life, which makes the heart ache worth it.

I could never imagine life without Macca, he was just meant to be here, all his strength and fight was worth it.

His big brother Keiran, youngest brother Alex and little sister Somer-Rose just love him too bits. His dad and I are just the most proudest parents.

Thanks for all your hard work and support; you do make a difference to families like ours

With love and best wishes always, Sharon Hayes

Any one else who wants to share any stories, we'd love to hear from you

EASTER PARTY—APRIL 2ND 2006

The Easter party was held on the 2nd April, the party was in a lovely big room with lots of fairy lights. There was loads of things going on, a tombola, raffle, face painting, magic show and disco hosted by Dippy the clown! Plus plenty of tasty food.

The mayor of Sandwell was the judge for the Easter bonnet parade. He said it was a very difficult choice with so many lovely entries!

Everyone had a really great time and took home a big Easter egg at the end of the afternoon.

We really enjoyed our afternoon there a big **THANK YOU**, to Sam Owen (Trustee) for organizing such a great party.

From: Joy Kortbeek (Member)

